

Open Research Online

The Open University's repository of research publications
and other research outputs

Growing Up With HIV: Exploring the Experiences of the First Generation of Perinatally Infected Young People in the UK

Thesis

How to cite:

Dorrell, Judith (2010). Growing Up With HIV: Exploring the Experiences of the First Generation of Perinatally Infected Young People in the UK. PhD thesis The Open University.

For guidance on citations see [FAQs](#).

© 2010 The Author



<https://creativecommons.org/licenses/by-nc-nd/4.0/>

Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0000eb29>

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk

Growing Up With HIV: Exploring the Experiences
of the First Generation of Perinatally Infected
Young People in the UK.

By Judith Dorrell

RGN, CQSW, BSc.(Hons.), MSc.

Submitted for the Award of:

Doctor of Philosophy

Faculty of Health and Social Care

The Open University

September 2009

DATE OF SUBMISSION: 29 SEP^T 2009

DATE OF ARCHIVE: 9 SEP^T 2010

Abstract

This thesis explores the experiences of young people perinatally infected with HIV in the UK. Although advances in medical treatment have made a major difference to the life expectancy of these young people this may not be matched by their 'lived experience' insofar as they face the consequences of a stigmatised disease as well as an uncertain future. This is the first study to critically analyse young peoples' accounts of growing up with HIV in the UK. This thesis considers the experiences of twenty-eight young people between the ages of fifteen and twenty-four recruited from a London hospital. Drawing on Bury's (1982) concept of 'biographical disruption' and the concept of 'critical moments' (Thomson et al. 2002), it explores how HIV affects a young person's biography.

Findings from the study demonstrate that a diagnosis of HIV disrupts biography and this experience is interspersed by 'critical moments' that serve to bring into sharp relief difference and forces young people to continually re-evaluate and make sense of being HIV positive. Young people make sense of disruption in order to construct and maintain a new identity as they become adults; this process is influenced by the stigma attached to HIV as well as by the disease trajectory. They use a range of strategies to adjust to and manage living with a stigmatised identity. This study raises important questions about the impact of HIV on young people, their families and their relationships. It demonstrates that most young people learn to 'pass' (Goffman 1963) as uninfected and conceal their HIV status. They withdraw from social relationships which increases their isolation and loneliness and affects their well-being. Findings also reveal that young people report little support to help them manage the impact of HIV. The study also highlights the urgent need for future research focusing on young people with HIV.

Acknowledgements

I would like to thank all the young people who agreed to participate in this study and shared their stories with me. I would like to thank my friends and colleagues Diane Melvin, Jo Dodge and The Open University for funding me to undertake this study. Thanks are also due to my husband and my family for their continuous support, encouragement and belief in me. Finally, my thanks to my supervisory team, Professor Shirley Reveley, Dr Jeanne Katz and Dr Sarah Earle for all their support, guidance and commitment to this research. This thesis is dedicated to the young people past and present who live with HIV.

Contents

Abstract

Acknowledgements

Chapter 1: Introduction	1
Background to the research	2
Overview of HIV	
Physical effects of HIV and treatment	5
Overview of chapters	7
 Chapter 2: Literature review	
Introduction	10
Context of HIV literature	11
Identity	12
Biography and young people	16
Disruption and stigma	23
Disclosure – the wider context	31
Emotional disruption of HIV	46
Making sense of illness	50
Summary	53
 Chapter 3: Research design and methodology	
Introduction	56
Background	56
Framework for the research	59
Design of the study	63

Analysis of the data	81
Summary	86

Chapter 4: Finding out or being told you have HIV infection

Introduction	88
Knowing, guessing or suspecting	89
Stories and explanations	97
Going to hospital is part of life	102
Having suspicions confirmed	103
Naming the difference	106
The formality of being told	109
Immediate reactions and responses	117
Summary	123

Chapter 5: Secrets and Lies

Introduction	125
Becoming HIV – becoming different	125
Learning about stigma and HIV	129
How the media do HIV	137
Strategies	140
Keeping secrets and lying in sexual relationships	151
Consequences of secrets and lies	154
Summary	159

Chapter 6: To tell or not to tell – disclosing an HIV status

Introduction	161
The dilemma of whether or not to tell others	161

There are risks if you tell	163
Those who do not tell	168
Those who tell	171
Bad experiences of telling	180
How participants tell others	185
Being born with HIV makes telling easier	188
Consequences of telling	190
Summary	195

Chapter 7: Making sense of HIV

Introduction	197
Religious narrative	198
Rationalisation narrative	205
Redemptive narrative	208
Positive narrative	213
Narratives about the past	219
Narratives about the future	222
Summary	230

Chapter 8: Discussion

Introduction	232
Biographical disruption and young people with HIV	233
Re-thinking biography and identity	240
Response to disruption and mobilisation of resources	245
Critical moments in young peoples' HIV trajectory	249
Key critical moments	250
Responding to critical moments	252
Influences on responses	253

The silent response	257
Summary	260
Chapter 9: Conclusion and reflections	
Reflections on methodology	263
Reflections on the contributions of the study	266
Areas for future research	270
Concluding remarks	272
References:	274
Appendix 1: Ethical approval	319
Appendix 2: Participant information sheet and consent forms	320
Appendix 3: Topic and interview guide	321
Appendix 4: Characteristics of participants	322

Chapter 1

Introduction

This thesis explores the experiences of young people living in the UK who were born with HIV. HIV/AIDS has been known for over twenty-five years. Globally there have been major advances in treatment; which has led to a decline in mortality rates and improved survival rates (Judd et al. 2007; Gibb et al. 2003). For many people, the introduction of highly active antiretroviral therapy (HAART) has transformed HIV from an acute terminal illness into a chronic condition (Fielden et al. 2006). There has been a dramatic reduction in the incidence of children becoming infected at birth (mother to child transmission) and as a result of effective treatment, children and young people are now living longer, healthier lives in resourced countries (Brown et al. 2000; de Martino et al 2000; Gibb et al. 2003; Foster and Lyall 2005; Judd et al. 2007; Sharland et al. 2002).

It is estimated that there are over two million children living with HIV and young people under the age of twenty-five are said to account for half of all new HIV infections worldwide (UNAIDS. 2008). The UK has a very small number of those infected; up to March 2009, there were 1560 children (CHIPS Data 2009) who live with HIV, most having been infected at birth (Brown et al. 2000; Gibb et al. 2003). Of these, 61% (951) are over the age of 10. Perinatally infected young people are an important and sometimes forgotten part of the AIDS epidemic (Bell et al. 2003; Cooper et al 2007; Fielden et al 2006). Although not an increasing population in the UK; the number of perinatally infected young people is expected to increase in less resourced countries, such as South Africa, where numbers are expected to double by 2020 (NAM 2009). The findings from this thesis therefore, although primarily relevant to the situation in the UK, may have significant implications for less resourced countries.

In the UK children and young people predominantly receive care in specialist centres, separate from adult HIV services (Foster et al. 2007). They are variously described in the literature as 'teenage survivors', 'retrieved children' or 'long term survivors' as they constitute the minority of children born with the infection that have survived (Cooper et al. 2007; Lyon and D'Angelo 2006). In general, children do not live as long as adults after contracting the infection; nor do they have the years of hidden, symptom free, infection enjoyed by many adults (Cooper et al. 2007).

Young people with HIV in the UK are not a homogenous group and come from diverse ethnic backgrounds. Many parents of infected young people originate from countries outside the UK, mostly from African countries. However most of these children and young people have been born or have lived in the UK for many years (Conway 2006; Lewis 2001; Miah 2004:15; Green and Smith 2004:34).

1.2. Background to the Research

My interest in this research stems from having worked in the HIV field for over twenty years, both in the UK and internationally. During this time I became increasingly aware that young people born with HIV are a hidden section of the HIV population. The impetus to begin this study came from an international workshop I co-organised in 1999 whilst working for the European Forum on HIV/AIDS Children and Families. We brought 24 HIV positive young people (aged 10-17years) from 6 European countries together for a week-long residential workshop. One of the main themes to emerge was the similarity of the young peoples' experiences across cultures. Their key message was how difficult and isolating they found living with HIV (Bond et al. 2000). The workshop demonstrated how little was known – apart from anecdotal evidence - about the lived experiences of young people growing up with HIV.

There have been several clinical studies on young people and HIV (Gibb et al. 2003; Judd et al. 2007; Walker et al. 2004) and some studies which examine family service provision in the UK (Lewis 2001; Conway 2006). However, there is limited research on the social and psychological impact of young people living with perinatally acquired HIV infection in the UK (Thorne et al. 2002; Green and Smith 2004). In fact, there is little research which draws directly on the experiences of young people with HIV since most studies have focused on adults or on the parent/carers of those with HIV. This study seeks to redress the balance and foreground the voices of young people living with HIV.

The conceptual framework used in this thesis draws in part on Bury's (1982) idea of biographical disruption and on the concept of 'critical moments' (Thomson et al 2002). Biographical disruption is a process where chronic illness disrupts different aspects of a person's biography. This process is interspersed by 'critical moments' that serve to bring into sharp relief difference and forces young people to continually re-evaluate and make sense of being HIV positive. Chronic illness is experienced as a 'critical event' and challenges a person's 'taken-for-granted assumptions' about their life. This leads to a fundamental re-thinking of biography and identity in the light of new information, which in turn leads to responding to the changed situation and the mobilisation of resources to deal with the altered situation in which people find themselves.

This exploration reveals how the stigma of HIV, which has been identified as one of its particular and defining characteristics (Sontag 1989), influences how biographical disruption and critical moments are experienced. The association of HIV stigma with sex, homosexuality and intra-venous drug use is extended to young people who are infected and the data emerging from this thesis raises important questions about how the stigma of HIV affects a person's view of self. Young people make sense of disruption in order to construct and maintain a new identity as they become adults and as the HIV disease process changes. Examining the personal experiences of young people born with HIV

also reveals complex relationships within families, particularly the relationship between mother and child.

This thesis explores the impact of the stigma of HIV and the resultant need to conceal a diagnosis which in turn complicates all social interactions. Those with perinatally acquired HIV are a unique population and are the first generation to experience growing up with the virus.

1.3. An overview of HIV: Setting the scene

In order to place this study in context a brief overview of HIV in the UK and the physical effects of the disease is presented. Historically, HIV services and care in the UK have tended to focus on adults, with children and young peoples' issues being somewhat marginalised. This has been in part due to the small numbers, but also to the dominance of adult services in this field.

The increasing demands of treatment and the development of complex drug regimens have led to the increasing prominence of the issue of disclosure and the rights of children to know about their illness. It has become crucial for young people to participate in decisions regarding their care and in particular for them to understand the need for adherence (Giacomet et al. 2003; Gibb et al. 2003; Naar-King et al 2006; Rosso et al. 2005; Thorne et al. 2000). This is because young people require a high level of adherence (95%) to treatment to prevent them developing drug resistance and also for the HIV drugs to be effective (Chesney 2003; Dray-Spira 2003; Giacomet et al. 2003; Steele et al. 2003; Van Dyke et al. 2002). If young people develop drug resistance fewer combinations of drugs are available to them and ultimately they may run out of options and become untreatable.

1.4. Physical effects of HIV and treatment

Young people are affected by the progress of HIV differently from adults and may experience a range of symptoms. This section describes the physical and clinical effects of HIV and does not address the psychological effects which are addressed later on in the thesis. Factors such as general health, nutrition and socioeconomic situation may influence the rate of progression of the condition (Lyon and D'Angelo 2008). The clinical course of HIV in young people with perinatally acquired HIV is very different from that of adults (Rodgers 2006). HIV affects the metabolic and endocrine function, alters hormonal development and affects growth and puberty development (Rogers 2006). Young people may experience constant pain, joint problems, and a range of immune related infections. HIV makes young people more vulnerable to infection as their immune system is compromised and therefore the risk of illness greater.

Most young people are on anti-retroviral medication by the time they enter their late teenage years (Rodgers 2006). Although the range of medication available has grown over the last ten years, most still have unpleasant side effects. Young people commonly report: lipodystrophy - that is the laying down of fat in particular areas of the body which can alter a young person's appearance and has been linked to poor self image, low self esteem, depression and sexual difficulty (McComsey and Ethan 2004:2; Murphy et al. 2003). Lipodystrophy has also been linked to increased levels of cholesterol and higher risk of cardiovascular disease (McComsey and Ethan 2004).

Young people also report experiencing sickness, diarrhoea, tiredness, depression, confusion, lack of concentration and skin problems such as rashes and warts (Lyon and D'Angelo 2008). Taking HIV medication is demanding, it has to be taken at very precise times and may involve being woken early in the morning or late at night. Historically the pill burden of HIV was high with up to eight or more tablets daily being common but, in recent years this has improved. As well as coping with side effects a high level of adherence (95%) is required to maximise the benefits of the medication and to avoid

developing the problem of drug resistance. Other side effects of treatment can result in young people being shorter than average and at greater risk of developing osteoporosis (Arpadi et al. 2002). The HIV virus has been found to delay puberty and sexual maturation in perinatally infected children (Buchacz et al. 2003; de Martino et al. 2001). Young people with HIV also report consistently high levels of pain, sleep disturbances and fatigue and depression (Brown et al. 2000; Gaughan et al. 2002; Lolekha 2004; Grubman et al. 1995).

Young people are likely to be familiar with the health care system as they will have been attending hospital regularly for monitoring and most will have had frequent hospitalisations (Lyon and D'Angelo 2008). Life expectancy for perinatally infected young people remains uncertain, it is less than those infected as an adult and some do not survive into adulthood (Lyon and D'Angelo 2008). Acquiring HIV perinatally means the virus has been present in a developing body and brain which results in a prolonged exposure to both the virus and toxic medication which subsequently impacts on a young person's health. There is emerging evidence of damage to the neuro-cognitive functioning of these young people which is of increasing concern to clinicians and increasing levels of psychological problems have also been reported (Sherr 2006; Woods et al. 2009).

Studies report evidence of cognitive damage and language delay among children and young people (Aldrovandi 2005; Brown et al. 2000; Gosling et al. 2004; Grubman et al. 1995; Letendre et al. 2009; Sherr 2006). Whilst new treatment has given many people hope, the long term effects of treatment and of the virus on young people are not yet fully known (Brown et al. 2000; de Martino et al. 2000; Gibb et al. 2003). For many young people their experience of HIV may be moving from one debilitating illness to another whereas a few may remain relatively illness-free. The general clinical picture is one of recurrent illnesses, compromised health and a greater likelihood of a premature death (Lyon and D'Angelo 2008).

The focus of this thesis is primarily on the experiences of young people living with HIV and does not include data on the clinical effects of HIV; the findings of this study however, act as a reminder of the physical consequences of HIV.

1.5. Overview of the chapters

This thesis presents the stories and the individual voices of young people, highlighting their views and experiences of living with HIV in the UK. Chapter two reviews the literature on the theoretical concepts of identity, biographical disruption, critical moments, stigma and disclosure in relation to HIV and young people. This chapter also introduces current areas of debate and key theoretical concepts particularly the idea of 'critical moments'.

Chapter three describes the process of deciding upon the most appropriate design and methodology for this study and the particular issues involved in undertaking research with young people who may be seen as vulnerable. The chapter includes details of the process of gaining ethical approval, describes the structure of the research design and explains the rationale for using a qualitative approach and individual interviews as a method of data collection. The chapter also explores the challenges and tensions encountered when moving from being a practitioner to becoming a researcher. It highlights the challenges in undertaking fieldwork in a clinical environment with young people.

Chapters four to seven present the data. These chapters describe the experiences of young people from learning that they are HIV positive to how they make sense of living with HIV. Chapter four begins with the experiences of being told, or finding out, about their HIV status. This includes those young people who suspected something was wrong with them before they were told, as well as those who were told accidentally. Young peoples' immediate responses and experiences are described as well as their reflections

on how they were told. In chapter five young people explain how and why they keep their HIV status secret and the strategies they use to keep their diagnosis hidden. The chapter also considers the stigma attached to HIV and how young people manage to conceal their HIV infection in different settings, including within their families. This is followed in chapter six with an exploration of how and why young people decide to tell others their HIV status and examines why some decide not to tell.

Chapter seven examines how young people make sense of HIV and the different meanings they ascribe to it. A range of narratives emerge from the data including a religious narrative and a rationalising narrative wherein young people explain that HIV is 'not the worst thing in the world'. Young people also find meaning through engaging in altruistic activities and wanting to create their own 'legacy' by making a difference. The chapter also explores the consequences for some young people of not being able to share their diagnosis; consequences that include feelings of isolation and sadness.

In chapter eight, using the concepts of biographical disruption, 'critical moments', stigma and identity, a discussion of the data demonstrates the complex lives of participants. The importance of the concept of stigma in relation to HIV is highlighted. In this situation, stigma leads to the need for secrecy which in turn disrupts a young person's biography. The need for secrecy means that all social interaction is potentially difficult for young people and they have to assess the possible risk consequences of disclosure. Biographical disruption is a dynamic process that is interspersed by critical moments that serve to remind young people of their difference and forces them to continually reassess their lives. How HIV affects a young person's identity is also explored in this chapter as the individual has to find ways of adjusting to an identity that includes HIV.

The final chapter concludes the study by reflecting on the process of the research and reviewing the primary findings. The chapter considers the methodological implications and

draws together themes that have emerged from the research findings. The limitations of the study are explained and areas for future research are suggested.

Finally, before turning to consider the literature, the terms used in this study include the phrase 'children and young people' and although the focus of the study is on young people, this phrase is commonly used in the literature and is therefore used where appropriate. Next, in order to place this study within the wider research context and highlight some of the current debates in this field, the following chapter reviews the literature from a range of areas pertinent to the experiences of young people with HIV infection.

Chapter 2

Literature review

2.1. Introduction

This chapter considers the literature on youth and the theoretical concepts of identity, biography, biographical disruption, critical moments, stigma and disclosure in relation to HIV and young people. These particular concepts have been selected because of their relevance to the themes that emerged from the data. The first section places the literature on HIV in context; section two considers the literature on youth and identity and the relationship between them and how a diagnosis of illness can result in an altered view of self. This is important because a diagnosis of HIV may alter a young person's identity, their view of themselves and how they perceive they are viewed by others. The next section explores the idea of biography and young people, biographical change and 'critical' moments'. The literature on biographical disruption is then considered and how this concept applies to young people, particularly those with HIV. Potentially HIV may bring about biographical change and disruption to young people and their experiences of disruption may be different from those of adults for a variety of reasons including the stigma of HIV and their youth. The fourth section investigates the nature of stigma in relation to HIV and whether stigma is a defining characteristic of HIV and influences the experience of biographical disruption. The wider issues of disclosure and young people are explored in the fifth part of the chapter, and specifically the literature on the disclosure of HIV to young people and their disclosure to others. The final part of this chapter reviews the literature on the emotional disruption that living with HIV brings; how individuals make sense of their condition and the potential mental health consequences of life with HIV.

2. 2. Context of HIV literature

Most literature on young people with HIV in the UK is medically focused because HIV is seen primarily as a medical condition (Thorne et al. 2002). Despite the high profile media coverage of HIV in the UK, (the National AIDS Trust reported at least one article a week on HIV), there is surprisingly little research on children and young people with this condition (NAT. 2009) and most research has focused on adults (Anderson and Doyal 2004; Cree et al. 2006; Elford et al. 2007; Green and Smith 2004). Children and young people are usually discussed in relation to the disclosure of parental HIV status or disclosure of an HIV diagnosis to a child (Lee and Rotherham-Borus 2002; Murphy et al. 2002a, 2002b; Waugh 2003). In the relatively rare studies where children or young people are the focus of the research, their experiences are usually mediated through parents or carers and the voices of young people themselves are seldom heard (Cree et al. 2006). Although studies of adults with HIV are of some relevance to this study, the experiences of young people with perinatally acquired HIV are unique because they have had HIV infection all their lives even though they may not have known.

In the UK non-clinical research on perinatally infected young people in the UK has tended to be policy and service driven rather than academic (Bond et al 2000; Lewis 2001; Miah 2004; Morton 1996); therefore most of the literature on young people and HIV comes from the US where the population of children and young people infected is larger. The two major English language reviews of studies of children and young people with HIV, one of young people with perinatally acquired HIV were from the US and Canada (Brown et al. 2000; Fielden et al. 2006). However, most US studies do not usually differentiate between those behaviourally infected and those perinatally infected; arguably the experiences of these two groups differ because the latter have lived all their lives with HIV and have not contracted it through sex, drug use or via blood products (Fielden et al. 2006; Melvin 2003). Having a serious health condition changes how individuals live and how they view themselves and whilst there is some literature on how HIV may change a person's view of

self and affects identity, these are predominantly studies of adults (Heaphy 1996; Tewksbury and McGaughey 1998). HIV is believed to change identity in that life is viewed differently for most people after diagnosis; The next section explores the literature on identity and young people.

2.3. Identity

Erikson (1956) observed that identity is difficult to categorically define because there are diverse and contested theoretical positions. He suggested that this is because identity concerns a process that is 'located in the core of the individual' and yet is also 'in the core of his communal culture' (Erikson 1956:22). Identity involves an interaction both between the internal development of an individual's personality and the sense of self that develops from participating in society the roles and cultural norms that individuals experience. Erikson viewed identity as shaped and modified by interaction between the individual and society, but suggested that there is an 'inner sameness and continuity' of one's own being (1956:313).

Identity theory can be traced back to Mead's work in 1934, when he established that an individual's identity consists of the 'I' and the 'me'. Collectively the 'I' and the 'me' constitute the self and interact with each other rather than conflict. Identities constitute who we are, personally the 'I', and socially the 'me', and a sense of self arises out of personal and social experiences (Tewksbury and McGaughey 1998). The 'me' includes the attitudes of oneself, the perceptions of others and of the wider community, whilst the 'I' part is the subject which actively experiences and acts on the social world. Mead suggested that 'Society shapes self shapes social behaviour' and differentiated between personal and social identity (1934:230). Personal identity is concerned with the internal processes of an individual, such as the way an individual defines, locates and differentiates themselves from others. Social identity concentrates on how social structures affect the structure of self and how this in turn influences social behaviour

(Stryker and Burke 2000). Taking a symbolic interactionist perspective, Mead established an understanding of the different elements that contribute to the concept of identity on which others have subsequently built.

2.3.1. Identity and Youth

One of the central characteristic that differentiates young people from adults is their youth, and how age affects identity has been the focus of much study. Erikson (1959,1980) highlighted the development of sense of identity as a crucial task for young people and observed that 'the process of identity formation depends on the interplay of what young persons at the end of childhood have come to mean to themselves and what they now appear to mean to those who become significant to them' (1977:106). Kroger (2004:20) suggests, that although Erikson (1977) considered identity as first evolving in the very earliest stages of development, rather than during adolescence; it continues to be reshaped throughout the life cycle.

Some theorists consider a young person's identity as viewed as a project that is in the process of formation and the stage between childhood and adulthood is a transitional one where their identity is incomplete (Kruger 2004). The sociology of youth highlights the importance of identity in the experiences of young people and how their very 'youth' is central to their experience (Thomson et al. 2002). The impact of events or a particular experience is considered more profound for young people because identity is in the process of formation therefore any major event is likely to have a significant impact on something that is not yet fully formed (Kruger 2004). The experience of chronic illness is likely to have a profound impact on a young person and their identity and a stigmatised condition, such as HIV, potentially more so.

2.3.2. Identity and Chronic illness

The relevance of identity theory to those with chronic illness is explored in the literature by Charmaz (1995,1997b). She suggests that the experience of chronic illness forces changes in identity because some aspects of a person's previous identity are lost, some remain and new aspects may have been added. These changes result in the re-defining of one's identity or some parts of it and creating a new identity based on the new situation (Corbin and Strauss 1987); a partial identity-transformation. These observations assume that identity is not fixed and illustrates the two central debates on identity; that is, whether identity is fixed or is something that changes as a consequence of experiences. If individuals have agency, it follows that critical events will impact on identity, and this leads to the consideration of the impact of critical events, such as illness (Heaphy 1996). Yoshida explained the impact of illness on a person's identity by developing the concept of a 'pendulum model of identity transformation' (1993:218). Her model conceptualises identity as a process where individuals move between sick and healthy identities which are experienced in both personal and social contexts.

Tewksbury and McGaughey (1998) suggest that the challenge for people with HIV is to construct an identity that is of value that includes their HIV infection, whilst also contending with the loss of anticipated future identities and roles. Charmaz notes that:

Identity is more than stable or discontinuous identifications of actions, attributes and statuses through time; it also accounts for an individual's aspirations and motivations for future identities. Hence, the concept of identity encompasses the person's vision of future selves, reflecting his or her hopes, aspirations, objectives and goals. (Charmaz 1987:284)

In the context of a critical life event such as the diagnosis or disclosure of chronic illness, such as HIV, identity may be disrupted in a number of ways; it can disrupt the present and

the future in terms of how the individual sees themselves, their personal identity, the 'I' part of self; and the 'me' part of self; that is a person's social identity and – potentially how they are perceived by others (Mead 1956). This concept is particularly relevant to HIV as the stigma of HIV may affect how an HIV positive person perceives they are seen by others. Scambler and Hopkins (1986) described this as 'felt stigma' where people fear the anticipated stigma as opposed to 'enacted' stigma where people actually experience stigmatisation.

A critical illness may disrupt future identities as well as goals and aspirations (Bury 1982; Charmaz 1983,1995, 1997b) which is of particular pertinence to young people who are at beginning of their life. Charmaz suggests for example, that potential future identities can be threatened and the activities and roles that form an important part of a person's identity, such as being a sister, engaging in a hobby or a job may be affected (1997). Previous studies demonstrate how chronic illness can potentially affect social relationships and precipitate changes in identity (Bury 1982; Corbin and Strauss 1987; Mathieson and Stam 1995; Yoshida 1993). Mathieson and Stam found participants' relationships changed when diagnosed with cancer; the 'identity altering' effects of illness curtailed their sense of agency and vision for their future (1995:300). Cancer disrupted participants' identity because they now inhabited a world of illness rather than one of health; resulting in a need to re-negotiate their identity (1995:296). Asbring (2000) found that women with chronic fatigue syndrome integrated a 'new identity' with an earlier one. She observes: 'women described either having two separate identities, of which one belonged to life before illness and one to life after, or experiencing a partial change in identity' (2000:318). This change in identity was precipitated by the disruption in their lives after illness.

The concepts of 'biography' and young people, 'biographical planning' and 'biographical disruption' are linked to experiences of chronic illness and a young person's identity and this literature is considered next.

2.4. Biography and young people

Biographical approaches to understanding the diverse experiences of young people have become an area of increasing interest and study by social scientists. How experiences influence and shape a young person's identity may be evident through key 'critical moments' and transitional points in their biography. Youth biographies are distinct from adult biographies, as they are in the process of formation as opposed to being fully formed. Du Bois-Reymond (1998) suggests that the life course of young people is a project in itself rather than just a transitional status between childhood and adulthood. It is seen 'as an autonomous phase' (1998:64) during which young people have to make choices. Building on Beck's (1992) idea of 'normal' and 'choice' biography, and reflecting on the changes in the life course of young people, du Bois-Raymond extends the idea of a 'choice' biography. He suggests that in western societies, there are increasing options for young people to choose from however, many feel ill-equipped to make the 'right' decision; it is the tension between the idea of freedom of choice and the difficulties that restrict choice that define choice biographies (1998:65).

The idea of choice biographies may be both socially and culturally positioned and appears to be more dominant in more affluent and more equal societies and less common in affluent countries with greater social division (Thomson 2008). As Bauman (1999:86) observes 'All of us are doomed to the life of choices, but not all of us have the means to be choosers'. The idea of choice is set against the influence of the social structures of inequality and there are a complex range of structural, resource and political factors that impact on choices available to young people in developing their biographies. Being young is associated with dependency and young people are commonly viewed as vulnerable by virtue of their age as they remain reliant on others for care, financial security and protection. They often have limited power and autonomy and may have little control over their circumstances or the decisions that are made by others that affect their life (Holland and Thomson 2009; Thomson et al.2002). These ideas are of relevance to individuals born with HIV as they live with the consequences of decisions made by other people.

Those with HIV also live with the disruption of a 'normal' biography and the potential loss of a choice biography as HIV restricts their choices.

Studies using a biographical approach rely on an acceptance of the meaning young people attribute to their lived lives and the decisions they made. As Thomson observes a biographical approach involves 'working with the meanings that young people attribute to their own lives, and revealing of issues of timing and circumstances' (2007:97). Although this approach assumes young people have 'agency' it does not ignore the structural inequalities experienced in young peoples lives that influence their decisions and choices.

Giddens (1991) described the relationship between self and structure as the 'project of self' which included certain events and experiences, which he refers to as 'fateful moments' defined as 'times when events come together in such a way that an individual stands at a crossroads in their existence or where a person learns of information with fateful consequences' (1991:113). According to Giddens, the individual needs to be aware of the significance of the event and be in a position to assess the risks of different choices and be able to act upon the decision they make. A 'fateful moment' demands agency, reflexivity and the insight and ability to undertake a risk assessment and exercise choice. An individual facing a 'fateful moment', according to Giddens (1991), must have some control over the event although some moments may be influenced by luck. 'Fateful moments' are seen as potentially empowering events as they bring the opportunity to develop new skills as individuals locate resources to respond to the new situation. Moments are considered to be 'fateful' when they have implications for both an individual's future behaviour and self-identity.

Chronic illness represents a significant event or critical experience for young people and one most see as beyond their control (Thomson et al. 2002). The experience of chronic illness or living with a life threatening health condition is likely to influence and change a young person's identity.

Youth studies research contains a strong focus on life course events and biographies, in particular key transitional events that occur in young peoples' biographies such as leaving home, moving from school to work and starting relationships. Such events result in biographical change in young people's lives and studies identify that there are key moments or experiences in young people's biographies that are significant and may leave a mark or alter their biography in a fundamental way. These experiences are referred to by researchers in a range of terms: Denzin (1989) refers to 'epiphanies'; others talk of 'critical moments' (Macdonald and Marsh 2005; Thomson et al 2002; Webster et al. 2004) and 'turning points' (Holland and Thomson 2009; Mandelbaum 1973). Humphrey (1993) views youth biographies as a 'social career' in which events or particular experiences are seen as a 'break' in the career.

Within a young person's biography, Thomson et al. (2002) argue, there are 'critical moments' that are provided by events or opportunities that present themselves that can result in a positive experience for the young person and the development of self. Such events can provide the momentum to experience change or force the transition to adulthood. 'Critical moments' can be both within or outside the control of the individual; those within an individual's control tend to be experienced as empowering, whilst those outside a person's control, such as illness, are linked with feelings of disempowerment (Thomson 2008). 'Critical moments' are important in that they highlight the influence of timing and circumstances and consider young peoples' subjective feelings. How young people respond to 'critical moments' is highly dependent on the resources available to them both on a personal and a social level. Whilst 'critical moments' are not spread evenly across the youth population as Beck observes (1992) neither are the range of choices nor the resources available to young people. As Holland and Thomson (2009) suggest, how a young person responds to events rely on the resources available to them, what they have to hand, as well as their ability to access them.

A biographical approach pays attention to detail and circumstances of a young person's life and their changing story. As well as the changes young people experience, the things that are constant and unmoveable for young people are also of importance in revealing the structural inequalities in their lives (Holland and Thomson 2009). The experience of a chronic illness or a diagnosis of a life threatening condition, such as HIV is likely to be experienced as a 'critical moment' for a young person, one that is beyond their control, and the potential influence of such a situation may extend beyond one event.

2.4. 1. 'Biographical disruption'

Whilst a diagnosis of HIV could be described as a 'critical moment' in a young person's biography, 'biographical disruption' is an appropriate conceptual framework within which to examine the experiences of young people with HIV. Biographical disruption is a process where individuals have to continually reassess and respond to the disruption a chronic illness brings. However within this process young people experience specific incidents which affect the nature of biographical disruption hence the application of the concept of 'critical moments' (Thomson et al. 2002). The diagnosis of HIV can be seen as 'a disruptive event' which consequently impacts upon most other areas of a young person's life. This disruption may be experienced differently to other conditions as HIV is stigmatised. Bury (1982) coined the term 'biographical disruption' to describe the disruptive experience of chronic illness. He identified that illness disrupts a person's sense of continuity, autonomy, control and meaning (Bury 1982). Bury suggested that the primary challenge for individuals with chronic illness is to make sense and ascribe meaning to their illness experience to re-discover their place in the world (1982). Chronic illness is a 'disruptive event' or a 'critical situation', and through his study of patients with rheumatoid arthritis, Bury (1982) identified three aspects of disruption; the disruption of 'taken-for-granted' assumptions and behaviours; the disruption of the explanatory systems that results in a fundamental re-thinking of a person's biography and self-concept; the response to the disruption which necessitates the mobilisation of resources

in the altered situation (Bury 1982:169). Bury suggests that chronic illness disrupts the structures of everyday life and 'involves a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others' (1982:169). Chronic illness draws into sharp relief an individual's mortality, and reminds people of the power and importance of stability in relation to the self, but as Becker observes, 'perhaps continuity is an illusion. Disruption to life is a constant human experience' (Becker 1997:190). How this disruption affects young people with HIV in particular is considered in the following section because it may be different to how adults experience disruption.

Biographical disruption, HIV and young people

The disruption an illness brings may be experienced differently by young people from adults for many reasons: they are at a young life stage and at an early part of their biography where they have only just begun to establish networks and resources. Their resources and responses may also be influenced by their age, experience of life as well as lack of established support.

Many researchers have developed and extended Bury's concept of biographical disruption (Williams 2000) and applied it to a range of conditions, such as stroke (Faircloth et al. 2004; Pound et al. 1998), chronic fatigue syndrome (Asbring 2001), Hepatitis C (Harris 2009) and HIV (Carricaburu and Pierret 1995; Ciambone 2001; Wilson 2007). However, all these studies focus on adults and as Williams observes, biographical disruption as a concept 'is predicated, in a large part on an adult centred model of illness' (2000:44). However, Bury's analysis of the disruption illness brings could arguably be relevant to children and young people as Dixon-Woods and colleagues (2002:175) observe:

Constructs such as biographical disruption, which are very prominent in adults' accounts of their experiences of chronic illness, also need to be explored from the perspective of children.

There are few studies on biographical disruption and young people (Grinyer 2007) and even fewer studies on biographical disruption and HIV (Carricaburu and Pierret 1995; Ciambrone 2001; Wilson 2007). Grinyer (2007) suggests that the experience of biographical disruption for young people may differ to that of adults. She argues that as young people with cancer are in a 'transitional life-stage' the disruption to biography caused by their diagnosis is more dramatic and can 'halt in its tracks, the young adult's life trajectory' (2007:266). The transition to adulthood and the associated tasks such as leaving home or becoming financially independent are all affected by illness- and the experience at this life stage 'can have chronic effects that extend beyond the illness period and have the potential to disrupt the life trajectory and biography in a profound sense' (Grinyer 2007:267). HIV represents a severely disruptive event, which has the potential to extend into the length of a young person's life, because it cannot be cured. Thus the potential for biographical disruption for young people may be exacerbated by their life stage and circumstances. As Bury (1982) observes, chronic illness can result in increased social isolation and withdrawing from friendships and wider social relationships, and for young people this may be of particular relevance when they are in the early part of their biographies.

Much sociological research has focused on the consequences on the lives and biographies of individuals with chronic illness and the effect illness has on identity (Bury 1982; Charmaz 1995; 1997). Studies on HIV and disruption have explored the impact it has on a person's identity (Carricaburu and Pierret 1995; Ciambrone 2001; Heaphy 1996; Hosek et al. 2002; Lightfoot et al. 2005; Tewksbury and McGaughey 1998; Wilson 2007). However, Bury suggested that the 'meaning of chronic illness lies in its consequences for the individual' (Bury 1982:453) and that different illnesses have different attachments to meaning and are accompanied by different stigma, moral judgements of cause and consequences.

The experience of chronic illness changes identity according to Charmaz (1987,1995), who observes how 'serious chronic illness undermines the unity between body and self and forces identity changes'. With young people identity, is more likely to be fragmented by illness than strengthened by it (Wilson 2007). Like Bury (1982), Charmaz argues that illness changes and challenges taken-for-granted assumptions about health, body and ones future health (1995). Chronic illness can disrupt the life course and challenges the 'normal' trajectory of adults (Bury 1982; Charmaz 1995), and for young people the normal trajectory is disrupted at an earlier stage. Part of the disruptive experience is adapting to, or acceptance of, living with a loss, a loss of the wholeness or completeness of the healthy self with the hope and future that is attached to the meaning (Charmaz 1995). HIV affects a person's life trajectory, disrupting their present and future plans and the medical and social aspects to the condition have the potential to radically alter a person's life (Carricaburu and Pierret 1995; Ciambrone 2001; Hosek et al. 2002; Tewksbury and McGaughey 1998; Wilson 2007).

Life stage and timing is identified by Wilson (2007) as significant in understanding the effect of disruption on identity. She challenges 'the universal expectation of biographical disruption' and suggests that where people are in their life-stage is relevant to how they experience disruption. This is particularly relevant to how young people experience a diagnosis of HIV. Wilson also suggests that the disruptive effects of HIV could be mitigated for adults by 'pre-existing identities' such as motherhood. Age has also been identified as mediating the disruption caused by illness. Pound and colleagues' study of older people who experienced a stroke found that the disruption wrought by the stroke was rationalised by a life time of difficult events and prior disruptions and an expectation of disruption of health in old age (1998:497). They suggested that the concept of biographical disruption appears to rely on the unspoken assumption that illness enters lives which have, until then, been untouched by disruptive events (Pound et al 1998). This finding was supported by Ciambrone's (2002) study of HIV positive women, many of whom had experienced disruptive lives prior to an HIV diagnosis. She found that HIV was

only one of many other difficult and disruptive life situations. However, Carricaburu and Pierret's (1995) study of asymptomatic HIV positive men found that although an HIV diagnosis disrupted participants' lives on an individual basis; HIV also 'reinforced' aspects of collective biography, such as identity around haemophilia or being gay. They concluded that biographical disruption as a concept may not be applicable to those who have prior experience of illness or prior disruption.

Several studies identify the context of disruption as significant (Carricaburu and Pierret 1995; Ciambrone 2001; Faircloth 2004; Harris 2009; Pound et al. 1998; Sanders et al. 2002). For example, Harris (2009), in her study of adults with Hepatitis C, found that the concept of biographical disruption was not equally applicable to all participants because some did not experience their diagnosis as a disruptive event. The contextual nature of biographical disruption is acknowledged by Bury (1982) and Williams (2000) extends Bury's concept and points out that: 'the biographical disruptive nature of illness is perhaps most keenly felt among the privileged rather than disadvantaged segments of society' (2000:50), because those most disadvantaged are likely to have experienced prior disruption. Williams also observed that Bury's concept has focused primarily on middle age rather than applied to either ends of the age spectrum; and has ignored genetic conditions and those conditions acquired from birth (2000). Bury's concept has rarely been applied to young people and has not considered the likely disruptive effective of a stigmatised chronic illness. The next section considers how disruption may be affected by stigma.

2.5. Disruption and stigma

HIV is recognised as a highly stigmatised disease (Lee et al. 2002; Herek 2002) and the particular nature of the stigma may affect how a person's biography is disrupted. Goffman described stigma as an 'attribute that is deeply discrediting' that reduces the bearer 'from a whole and usual person to a tainted, discounted one' (Goffman 1963:3). Stigmatised

people, according to Goffman, possess a characteristic defined as socially undesirable, such as HIV/AIDS, and acquire a 'spoiled identity' which leads to social devaluation and discrimination.

The stigma attached to HIV is a feature that defines the condition (Lewis 2001; Wiener 2007). Although there are shared ideas regarding specific attributes of a stigmatised person (Varas Diaz et al. 2005), Goffman argues that society manages this difference through rules and sanctions which results in individual and social identities being 'spoiled' and the stigmatised individual having to incorporate a negative view of the self (Goffman 1963).

The issue of visibility is central to Goffman's concept of stigma because persons whose stigma is clearly visible will be discredited by others, whilst those whose stigma is not visible are considered 'discreditable' since the possibility of being identified as 'stigma bearers is always imminent' (Goffman 1963:64). The importance of visibility of a stigma is evidenced in social interaction, and since stigmatising people are perceived as deviating from a social norm (Luchette 1999), it is their social interaction with others where this difference is evident. People may feel stigmatised without the presence of others (Crocker and Quinn 2000) by experiencing rejection or feeling despised (Hebl et al. 2000; Wiener et al. 1988), and those stigmatised have less power or influence in most social situations (Jones et al. 1984). Goffman suggests that individuals with a hidden stigma have the option of 'passing' as normal in order to avoid becoming discredited, and remain protected (Goffman 1963). 'Passing' may involve not talking about their stigma, hiding any reference to it or constructing an alternative story to explain any discrepancies. He observes that parents of children with 'concealable' stigma, are able to protect the child within a 'protective capsule' until they are deemed able to cope with the disclosure of their stigma (Goffman 1963:46).

Individuals with invisible stigma such as HIV/AIDS face challenges not experienced by those with visible stigma. Ragins and colleagues (2008) argue that although individuals with invisible stigma can conceal their identity in order to avoid potential negative responses, this is not without consequences (Ragins 2008; Smart and Wegner 1999; 2000). Maintaining secrecy and concealing a stigma can be hard work and stressful (Ragins et al. 2008; Wiener 2006).

Goffman's concept of stigma has been developed, extended and criticised. Parker and Aggleton (2003) suggest that his concept of stigma is limited because it views stigma as 'something in the person stigmatized rather than as a designation that others attach to that individual' (Link and Phelan 2001; Parker and Aggleton 2003:15). These authors take the concept of stigma beyond the behavioural perspective to consider notions of power and domination; they argue that stigma is not an individual process or 'what some individuals do to others individuals', because all stigma has a history and a story about when it appeared and the form it takes. They suggest that understanding this history and the consequences helps people develop better measures to reduce its effects. HIV-related stigma is seen by Parker and Aggleton as intrinsically linked to the politics of social exclusion and inequity in society (2003:16).

Whilst stigma may be experienced by an individual, Goffman (1963) suggests that the stigma of one individual can extend to family and social networks. This contamination of stigma, as Madru (2003) observes, can lead to the avoidance and ending of relationships with family and friends and can obstruct support systems for people with HIV (Abadia-Barreo et al. 2005; Madru 2003). Studies of young people and families in London illustrate this point as they found that the stigma of HIV often disrupted young people's family and social networks and reinforced the existing social isolation of families (Brown et al. 2004; Knight et al. 1999; Lewis 2001; Miah 2004). Young people were particularly isolated from the community because they feared being 'found out' (Miah 2004; Lewis 2001).

Goffmans' concept of stigma was further developed by Scambler and Hopkins (1986) in their study of adults with epilepsy. They introduced the distinction between 'felt' and 'enacted stigma'. They distinguished between enacted stigma, that is 'actual experience of stigma and discrimination', and perceived or felt stigma, that is the shame associated with the stigma and the 'fear or encountering enacted stigma' (Scambler 2004; Scambler and Hopkins 1986). Felt stigma is identified in studies on HIV/AIDS as especially important in as much as the individual is infected with a virus that can also be passed on (Pierret 2000). Scambler and Hopkins observed that perceived or felt stigma may lead people to shape their behaviours to avoid enacted stigma, but in doing so they may also limit the opportunities for support (Scambler 1984; Scambler and Hopkins 1986). The fear and anticipation of stigma results in people avoiding situations and social contact where there is the possibility of stigma arising.

The fear of enacted stigma was further developed by Scambler through his concept of a 'model of hidden distress' (Scambler 2004:30). Using epilepsy as an example he described the model as having three components: first on diagnosis of epilepsy, individuals learn that it is a 'liability' and is accompanied by a fear of enacted stigma; second, individuals develop 'a special view of the world' (Stebbins 1970) which leads to a concealment of their condition and attempts to 'pass as normal' (Goffman 1963)- whilst individuals are able to pass they remain discreditable rather than discredited; third, the concealment limits the opportunities for enacted stigma. Thus Scambler's model focused on greater understanding of the impact a diagnosis of epilepsy had on an individual's biography. Being diagnosed as having epilepsy led individuals to look at events in a new way and resulted in interpreting life mindful of their 'new and unwelcome identity' (Scambler 2004:33).

Further research from Berger and colleagues identified more subtle dimensions of HIV stigma as perceived by those with HIV. They identified four factors relational to HIV: individuals saw HIV as personalised stigma and feared social rejection; they identified

disclosure concerns and had a negative self image; they also were concerned with the public view of people with HIV (Berger et al. 2001). These factors are also evident in Swendeman and colleagues' (2006) study where they found that 89% of the 147 HIV positive young people they asked had experienced perceived stigma in the last three months and 31% reported experiencing enacted stigma (Swendeman 2006:501). They also found that HIV stigma does not need to be enacted for young people to report being fearful of HIV stigma and related discrimination (Swendeman 2006). They concluded that felt stigma is highly influential in young people's disclosure decisions and led them to disclose less (Swendeman 2006:10). They also observed that whilst this self protective behaviour prevents disclosure, it also results in young people having little access to support and care. The fear of stigma may further isolate young people from social networks in their attempt to avoid the risk of stigma (Swendeman 2006:11). Young peoples' biographies are disrupted by HIV because they have to alter their friendship and support networks to accommodate the stigmatising nature of the condition. Swendeman found that young people found managing the stigma of HIV stressful; it created emotional distress which impacted on how they coped with HIV.

Given the stigmatising discourse that has grown up around HIV, the experience of disruption this condition brings may be different from that of others. Fife and Wright compared the impact of stigma on people who had HIV with those with cancer. They found that people with HIV/AIDS reported stronger feelings of stigma than those with cancer, but that the nature of the illness 'has few direct effects on self-perception' (2000:65). How society views HIV is identified in the literature as significant in how individuals with HIV view themselves, and this is considered next.

HIV - a stigmatised illness

A number of illnesses have been associated with stigma such as mental illness (Corrigan and Penn 1999; Goffman 1961), cancer, leukaemia (Fife and Wright 2000), epilepsy

(Scambler and Hopkins 1986), deafness (Becker 1981), rheumatoid arthritis (Bury 1988), and autism (Gray 2002). However HIV is perceived to be viewed differently. Studies have suggested that it is the level of social stigma associated with HIV that sets it apart from such other conditions (Bor and Elford 1998; Cree et al. 2004; Fife and Wright 2000; Mason et al. 2001; Ogden and Nyblade 2005; Petty 2005; Sontag 1978; Wiener 2006).

The literature on HIV identifies four characteristics that account for why it is so stigmatising: first it is perceived as incurable, progressive, degenerative and associated with death (Herek 2002; Lee et al. 2002; Murphy 1995; Alonzo and Reynolds 1995; Cogan and Herek 1998; De Bruyn 1998); second, the notion that those who are infected 'got what they deserved' because of their activities (Chapman 2000; Sontag 1989; Alonzo and Reynolds 1995) is another key characteristic and these activities are seen as avoidable, voluntary and the responsibility of the individual- stigma is greatest when related to medical conditions associated with deviant behaviour or where the cause is viewed as the individuals own responsibility (Alonzo and Reynolds 1995); third, HIV is associated with stigmatizing behaviour such as same sex relationships, drug use, unsafe or high risk sex and irresponsible sexual behaviour and promiscuity, the last being particularly associated with women (Bunting 1996; Lee et al. 2002; Lewis 2001; Sontag 1989:25; Swendman et al. 2006; Wiener et al. 2007a); fourth, HIV is contagious, and contagious conditions carry a greater degree of stigma. The fear of infectivity and contagion, Sontag (1989) argues, influences the level of stigma attached to HIV that has not been attached to any other disease in recent times (Herek et al. 2005; Lee et al. 2002; Nagler et al. 1995). The idea that HIV positive people place the rest of society at risk of infection is an important element in understanding HIV - related stigma (Bunting 1996; Chapman 2007; Ciambrone 2001; Deacon 2005; Herek 2002; Ostrom et al. 2006). Similarly, Stangor and Crandell (2000) argue that the perception of threat appears to be a likely foundation of stigma. How this relates to young people is considered below.

Studies with HIV infected young people demonstrate that HIV is experienced as a highly stigmatising disease in society (Bond et al. 2000; Lewis 2004; Wiener 2006; Ostrom et al. 2006). UNAIDS consider that the social construction of HIV related stigma has been 'nurtured by social fear, ignorance, anxiety, lack of knowledge, denial, shame, taboo, racism and xenophobia, and moral judgements' (Malcolm et al 1998; UNAIDS 2002), and by metaphors like death, punishment, crime, 'otherness' and shame (Sontag 1989). Sontag observes that HIV and AIDS has become society's most stigmatised disease whereas cancer previously fitted this definition (Sontag 1989). She argues that it is the moral dimension of HIV that sets it apart from other chronic illnesses, and impacts on those infected (Sontag 1989; Wiener 2000). As Sontag notes, a moralising discourse has developed around HIV, with talk of deviant behaviour, guilt and blaming on the individual:

The unsafe behavior that produces AIDS is judged to be more than just weakness. It is indulgence, delinquency – addiction to chemicals that are illegal and to sex regarded as deviant. (Sontag 1989:111)

Illnesses such as HIV carry meanings other than medical, and the illness becomes a metaphor for characteristics attributed to the person (Sontag 1989). Those who contract the illness may be judged culpable. As Frankenberg (1986) observed the illness experience forces the individuals to cope with not only the illness, but also the metaphors produced and imposed by society (Frankenberg 1986; Sontag 1989). The blame on the individual for acquiring HIV in certain ways has been ranked in some research, for example, - Herek and Capitanio (1998) found that people with HIV are subject to different 'layers' of stigma according to the route of infection; being infected through sex with multiple partners was viewed more negatively than those infected through sex with one partner. Of those contracting HIV through sex: gay, bisexual men were viewed more negatively than heterosexual women or men. This moral hierarchy reinforces what is considered desirable sexual behaviour.

The pattern of blaming others in discourse about disease that Joffe (1999) termed the 'not me – others are to blame' phenomenon is prominent in the HIV literature and has been identified by a number of researchers (Crawford 1994; Joffe 1999). The process of blaming others involves attributing risk characteristics and behaviour to 'others' or other groups (Deacon 2005). This can be observed in studies that have identified a range of groups that have been defined as particularly at risk of, and somehow responsible for, contracting HIV/AIDS, including African people, promiscuous gay men, commercial sex workers and women (Deacon 2005; Joffe 1999). The social discourses that have developed around death, fear and deviant behaviour and the potential danger and threat related to those with HIV characterise the stigma attached to HIV (Pierret 2000).

Metaphors about HIV have developed and been extended to those with HIV being viewed by society as polluted and dirty unlike individuals with other conditions (Fee and Fox 1992; Grove et al 1997). Lupton's (1999) study of the Australian Press coverage of HIV in the 1990s highlighted the themes and metaphors that were common at the time, such as plague, dirt, pollution and contamination (Sontag 1989; Gilman 1988). The issue of stigma and negative representations have particular resonance when combined with specific embodied aspects of HIV. The body of the person with HIV can then be perceived as dangerous, contagious and a threat to others, a body that people want to avoid and do not want to touch (Chapman 2000).

Once someone with HIV is positioned as 'Other' (Joffe 1999), it becomes easier to denigrate and exclude them. HIV is seen to affect already stigmatised groups of society, such as gay men, prostitutes, the poor and IV drug users, and the negative representation of HIV through media images, metaphors and language re-enforces those with HIV as the 'Other' (Crimp 2004; Lupton 1994; Gilman 1995). Chapman's study of the impact of negative media representation of HIV argued that through the process of internalisation there is also the potential for individuals to feel themselves as the 'Other' (Chapman 2000; Joffe 1999). Individuals are vulnerable to 'self-hatred' which can arise when they

internalise society's negative view of them (Lee et al. 2002:315). The negative representation of HIV in the media is noted in some literature as significant in re-enforcing the stigma attached to HIV (Juhasz 1993; Lupton 1994; Sacks 1996; Wilson 1997).

The stigma of HIV has been identified as highly significant in decisions that individuals make about disclosure (Batterman et al. 2005; Green and Smith 2004; Landau and York 2004; Petrak et al. 2001; Wiener et al. 2007b). However, the general issue about disclosure of illness to children and young people is discussed in a range of literature and considered in the following section.

2.6. Disclosure – the wider context

Much of the literature on the disclosure of serious illnesses to children who suffer from such an illness has been influenced by paediatric oncology where the most extensive studies have been conducted (Wiener et al. 2007b). In the 1960's telling children about their illness was not usually advised by doctors, who tended to see this as adding to the distress of the child (Share 1972). Different approaches have developed subsequently moving from the 'protective approach' in the 1960's, when it was thought in the child's best interests to have little or no information, to a more 'open approach' where children, parents and clinicians began to move towards increasingly open communication (Waechter 1973; Chesler et al. 1986). As a result of research with children views about talking openly to children about illness and treatment has changed, and it is now seen and recommended as 'good practice' for health professionals to support parents to talk openly to their children about their condition (British Medical Association 2001; Scott et al. 2003; Clarke et al. 2005). To be able to talk openly and honestly about illness is seen to help provide the best emotional and psychological care for both the child and family, as it reduces the need for lying and pretence (Dahlquist and Taub 1991; Chesler et al. 1986; CHIVA 2009; Spinette 1974).

Paediatric oncology research, such as Bluebond-Langner's (1978) study on terminally ill children, added to the belief that it was also beneficial for children with chronic illnesses to be told their diagnosis. In her study of children with leukaemia the problem of what to tell the children focused around the issue of protection, and the children took the initiative to discover what was wrong rather than parents telling (Bluebond-Langner 1978:227). Disclosure was beginning to be linked with positive adjustment in children and families, with growing evidence of the positive benefits lasting into adulthood for both the child and family (Chesler et al. 1986; Slavin et al. 1982; Katz and Jay 1984). Research carried out with children with cancer, such as that by Lipson (1994) found that disclosure lessened children's feelings of isolation, distrust and confusion.

Whilst studies on disclosure revealed positive benefits for children, the research also suggested that children who had not been told their diagnosis may have already known or at least suspected what was wrong (Chesler et al. 1986; Bluebond-Langner 1978). The literature on this, known as 'awareness context', is considered next.

Knowing and suspecting: awareness contexts

There is a large body of literature on knowing or suspecting in relation to serious illness in adults but less on children and young people. Studies of children with cancer illustrate childrens' capacity to understand the nature of their illness long before they have been told (Bluebond-Langner 1978, 1990; Chesler et al. 1986; Clafin and Barbarin 1991; Spinetta 1974). Research findings suggest that giving little information to a child or young person, or not providing an opportunity for them to ask questions about their illness, does not protect them from fear or worry. Young people are able to 'sense' whether it is safe to speak about an illness; they learn that the illness is a 'secret' and that they should not ask questions. In fact it is what Clafin and Berbarin (1991) call a 'dangerous secret'. Studies also show that children and young people pick up information and cues from their illness

experiences through regular visits to hospitals or medical tests; children report overhearing parents and doctors talking and draw their own conclusions about the child's illness (Clarke et al. 2005; Bluebond-Langner 1978; 2004). Waechter's study on death anxiety and children, found that children showed 'acute awareness of anxiety' about their condition, despite their parent's stance of not talking to them, which the authors saw as protective communication (Waechter 1973; Chesler et al. 1986). Although studies on HIV and disclosure reveal that there are similarities in the disclosure experience of children with HIV and other chronic illnesses (Lee and Rotherham-Borus 2002; Wiener et al. 2006, 2007), Lesch and colleagues found that:

HIV infected children are generally less likely to be told of their illness compared than those with other illnesses, eg cancer. (Lesch et al. 2007:812)

Lesch and colleagues attribute this reluctance to the fear of the stigma of HIV. Bluebond-Langner's (1978) study provided an important insight into the awareness of children. She developed and applied the concept of 'mutual pretense' from Glaser and Strauss's 1965 study on terminally ill adults and awareness contexts to children.

In their seminal study, Glaser and Strauss (1965) identified four types of awareness contexts: first, closed awareness where 'the patient does not recognise their impending death, even though everyone else does' (Glaser and Strauss 1965:11), through to second, an open awareness where 'personnel and patient both are aware that he is dying, and...they act on this awareness relatively openly' (Glaser and Strauss 1965:11). In between these two contexts lies a third 'suspicion awareness', wherein 'the patient suspects what the others know and therefore attempts to confirm or invalidate his suspicion' (Glaser and Strauss 1965:11) and fourth, 'mutual pretense', wherein the patient and others are aware the patient is dying but act as if it were otherwise 'when both agree to act as if (he) were going to live' (Glaser and Strauss 1965:11). They argued that these

positions are maintained by the control of information given to the patient by medical staff and by following certain communication and behaviour rules, which are governed by who knows what. To maintain the contexts where individuals suspect or pretend, nothing must be done to arouse suspicion, because this situation, is what Glaser and Strauss refer to as a 'delicately balanced drama'(Glaser and Strauss 1965:12).

Field and Copp (1999) added to the debate by suggesting that an open awareness may not be always desirable, and for some individuals it may be difficult to continually sustain an open awareness (Field and Copp 1999, 2002:118). They suggested that for some individuals, denial and acceptance are useful strategies to use alongside an open awareness, to enable them to cope with their situation and circumstances (Timmermans 1994; Field and Copp 1999; 2002).

Whereas most studies on context awareness were primarily focused on adults, Bluebond-Langner studied children. She observed that children also function within similar context awareness. She suggested that parents participated in the mutual pretence process by indicating their unwillingness to talk when children asked questions about their health. They gave children little information, explained little and avoided the subject as much as possible. Children also observed the behaviour of their parents such as: leaving the room; minimising contact; avoiding any discussions of their condition or particularly dangerous topics and anything related to the subject, and interpreted this as further evidence of their parents' unwillingness to talk about their condition (Bluebond-Langner 1978:201).

Bluebond-Langner identified 'rules' that adults seemed to follow, such as: keeping the interaction as normal as possible; avoiding information slips about the condition; keeping interaction short, and where interaction becomes very difficult, trying to end it or use avoidance or distancing strategies. She found that children used avoidance strategies such as refusal to talk, or talking about anything but their condition and/or distancing themselves through silence or anger in response to this distancing behaviour of adults

(Bluebond-Langner 1978:207). Children interpreted the silence of adults and changes in behaviour of those around them as connected to their condition and linked this to their unwillingness to talk. Children in her study were aware of their condition and she observed that they concealed this from others and, in turn this was concealed from them by others. She suggested that whatever form of interaction occurred children were not freed from conflict because even the decision to reveal one's condition was fraught with risks and difficulties as it presented children with the dilemma of who to tell. She found that the needs of the children were often in conflict with those of their parents; the children knew what their parents knew, but also what they wanted to hear. Although children kept their awareness hidden, she observed that they would often like to share that information with someone else (Bluebond-Langner 1978:235).

Subsequent studies have reported similar findings; Chesler and colleagues (1986) found that one of the unintended consequences of delaying disclosure to children with cancer was that the children made up their own story of what was wrong. Where children and young people do not ask questions and are silent this is often taken as an indication by adults that they do not want to know about their condition (Beale et al. 2005; Share 1972). Childrens silence in the face of knowing about their situation is explained by Bluebond-Langner by them observing a mutual pretence strategy, where children pick up cues, listen to talk and observe and interpret the actions of the adults around them (1978:8), which in turn enables them to make sense of their experience. She argues, as do many others, that children and young people are competent interpreters of their world, and as such interpret what they observe (Bluebond-Langner 1978; Deatrick and Faux 1991; Sartain et al. 2000).

Studies of children and young people with HIV present a mixed picture of the information they have of their condition before they are told. Several studies identify the patterns of communication about HIV to children as characterised by reluctance to discuss the subject (Weiner et al. 2007b; Lewis 2001; Conway 2006; Miah 2004). Other studies

suggest that children and young people may have more understanding than adults realise regarding their HIV status even though it has not been formally spoken about (Landsdown 1994; Lipson 1993; Waugh 2003; Wiener et al. 2006, 2007b). Instone's small study, which analysed children's drawings, found that children expressed feelings of loneliness, sadness, and a fear that they were aware of something being wrong with them but that they 'sensed' they could not discuss their concerns with their parents (Instone 2000).

Hardy and colleagues' study (1995) illustrated how childrens awareness and knowledge may be communicated in different ways. They looked at communication patterns with three groups of twenty children, one with cancer, one with HIV and a control group of healthy children. Nineteen of the children with cancer knew their diagnosis as did five in the HIV group. The children were asked to place dolls representing the child, parent and staff in a task. Children with cancer put the dolls representing the staff and parents significantly closer to the child doll than children with HIV. Significantly children with HIV removed the staff and parent dolls from the room or turned the parent and staff doll's back to the child doll, reflecting a common practice of talking about a child's HIV status in whispers or outside the room, and as Weiner and colleagues observe 'suggesting that communication around the child is closed and isolating' (Hardy et al. 1995; Wiener et al. 2007b; Waugh 2003). The difficulties reported in the literature that parents have with talking to children and young people about HIV is key to my study, and the issues raised in the previous literature continue into the next section where material on the disclosure to children and young people is explored.

Disclosure to young people

Disclosure to young people about HIV has been influenced by the development of new treatment available for children and young people (Brown et al. 2000; CHIVA 2009; Thorne et al. 2000, 2002) because the complex drug regimens and adherence have resulted in the need for children and young people to participate in decisions about

treatment and care at an earlier age (Thorne et al. 2000; Melvin 2003). Thus the issue of disclosure and the rights of children to know about their illness have been increasingly important (Gibb et al. 2003). Telling a child an HIV diagnosis has been consistently highlighted in the literature as a difficult and emotionally laden issue (2007b; Murphy et al. 2000; Melvin 2003; Lester et al. 2002; Wiener et al 2006).

In the UK, studies reveal complex cultural patterns and contexts for young people with HIV and some studies have highlighted how this can affect disclosure decisions within families (Anderson and Doyal 2007; Conway 2006; Lewis 2001; Melvin 2007; Miah 2004). There is a high proportion of young people with HIV that are first generation immigrants from African countries (Green and Smith 2004; Lewis 2001; Melvin 2003; Melvin 2007; Miah 2004; HPA 2006; NAM 2006), and research findings suggest that families from different cultures may view childrens inclusion in decisions and the need for disclosure differently from those of the medical profession (CHIVA 2009; Miah 2004; Melvin 2007).

Chesler and colleagues (1986) along with others, have found age to be a significant factor in disclosure in cancer and likewise researchers have found the same with HIV (Clarke et al. 2005; Melvin 2003; Nöstlinger et al. 2004; Rotherham-Borus et al. 1997; Thorne et al. 2000; Wiener et al. 1996; 2006; 2007b). These findings indicate that young people should be informed about their status before they are teenagers or before they become sexually active. Melvin (2007) draws attention to the potential difficulties young people may have to deal with if not told at a young enough age:

It can be overwhelming and unfair for older teenagers to have to cope with learning they have HIV infection, which is a chronic and health threatening condition that it is transmissible, when they are dealing with hormonal changes, growing independence and sexual development, and changes in peer and family relationships. (Melvin 2007:3)

Wiener and Battles (2006) found that young people who had learned of their diagnosis 'younger' had disclosed to more people. Thorne and colleagues (2000) undertook a ten country European study of patterns of HIV disclosure and found, like others studies, that age was a key factor in disclosure (Rotherham-Borus et al. 2005; Wiener et al. 1996). They found that sixty per cent of infected children over eleven had been told their diagnosis and observed:

This finding is similar to that reported for HIV infected children in the USA where half the 11 year olds enrolled in clinical trials had not been told that they were infected despite the rigors of trial participation. (Thorne et al. 2000:4)

Thorne's study supports other research that suggests that adults find it difficult to talk to children and young people about HIV (DeMatteo et al. 2002; Lester et al. 2002; Feldman 2003; Fielden et al. 2006; Melvin 2006; Rotherham-Borus 2003; Wiener et al. 2006, 2007b). The literature around HIV disclosure highlights the complex and trans-generational nature of the issues for children and young people who have acquired HIV perinatally, because disclosure presents parents with the difficulties of a double disclosure, revealing maternal (and possibly paternal) infection. (Miah 2004; Thorne and colleagues (2000) and Wiener and colleagues (1996; 2000; 2006; 2007b) These studies found that the disclosure of HIV often leads to revealing other family secrets, particularly in relation to maternal infection, and may raise unresolved issues, for example, about sexual relationships, and drug use in families (Brown et al. 2000; Green and Smith 2004; Fielden et al. 2006). The majority of children acquire the virus from their mothers and the ensuing parental guilt about transmission distinguishes this disease from cancer and other life threatening illnesses, and affects disclosure decisions (Brown et al. 2000; Fielden et al. 2006; Green and Smith 2004; Wiener et al. 2007b).

Lesch and colleagues (2007) asked parents why they delayed telling their child about their HIV diagnosis and found that parents feared the emotional consequences; they feared being blamed and rejection, and distressing the child. This supports previous findings by Wiener and colleagues (Lesch et al. 2007; Lester et al. 2002; Wiener et al. 1996; 2006; 2007b). These studies found that the fear of stigma and the potential negative impact on families and children were key reasons for delaying disclosure, and parents cited avoiding distress for their child and fear that the information might cause depression or deterioration in the child's health as the main reasons (Brown et al. 2000; Fielden et al. 2006; Lewis 2001; Lyon and D'Angelo 2006; Nöstlinger et al. 2004). Not being told the whole truth is also identified in some studies as significant to children and young people when told their diagnosis (Conway 2006; Bond et al. 2000; Instone 2000). It seems that parents often feel ill-equipped to discuss the issues with children and fear they themselves will break down whilst telling the child (Young et al. 2003). Nevertheless parents are the gatekeepers of communication and manage the exchange of information between doctors and children (Conway 2006; Bond et al. 2000; Lewis 2001; Clarke et al. 2005; Miah 2004).

The disclosure of HIV is rarely a single event. As Lipson and others suggested in the early 1990's it should be viewed as a process rather than an event; most often the process begins with partial information (Lipson 1993:1994; Lesch et al. 2007; Melvin 2004). Funck-Bretano (1997) was one of the early researchers in HIV to identify various patterns in disclosure; 'partial' disclosure being the most common. This pattern seems to be sustained as Wiener and colleagues (2007b) found in their review of disclosure studies, partial disclosure was often used to delay telling a child or young person their diagnosis, and further conceal the condition. Funck-Bretano (1997) found that it was often linked with illness deception where parents motivated to protect their child, tell them about a less serious condition and attribute medical interventions to a less stigmatised condition (such as asthma). Instone (2000) and others identified similar patterns of behaviour and

'illness deception' in their studies, wherein parents linked medical treatment with a non stigmatised, but related condition (Wiener et al. 2007b).

Studies of adult reactions to the disclosure of a life threatening disease and highly stigmatised conditions such as HIV have included shock, denial, and anger (Gielen et al. 1997). Squire noted in her study how adult participants experienced shame, fear and despair after an HIV diagnosis and felt themselves to be dirty and visibly contaminated (Squire 1997). Studies that have considered the psychological impact of disclosure on young people report it as a distressing experience with young people reporting feeling sad, worried, and upset (Bachanas et al. 2001; Blasini et al. 2004; DeMatteo et al 2002; Funck-Brentano et al. 1997; Wiener et al. 2006; 2007b). HIV positive young people are reported to have similar reactions to those reported by children following disclosure of leukaemia and cancer diagnosis (Clarke et al. 2004; Scott et al. 2003). However, not all responses are the same; some young people reported feeling overwhelmed by a sense of isolation and abandonment, as they felt the label of being HIV positive engulfed their previous identities (Barroso and Powell-Cope 2000).

Whilst the literature identifies age as a factor in when young people are told their diagnosis, there does not seem to be an established link between the age of disclosure and subsequent psychological distress. However, Wiener and Battles in their study of forty adolescents, suggest that 'greater disclosure is associated with better psychosocial outcomes' (2006:309). These findings are corroborated in other studies (Frink Sherman et al. 2000; Wiener et al. 2007b; Rotherham-Borus et al. 2005). The wider literature also suggests that children and young people who learn about their diagnosis (cancer and HIV) in an open and supportive way appear to adjust better psychologically, and some studies even suggest that young people with cancer, who were misinformed or learnt their diagnosis at a later stage did not adjust as well (Blasini et al. 2004; Slavin et al. 1982; Nöstlinger et al. 2004, 2006).

Disclosure has been found to be 'a positive factor in long term survival and decreased problem behaviour in adolescents, and is positively associated with social support and self confidence' (Battles and Wiener 2002:161). The evidence from adult HIV studies also suggests that improved knowledge and better understanding of illness is associated with improved compliance and better health outcomes (Marellich and Murphy 2002; Mayfield Arnold et al. 2008), and there is increasing evidence from studies on children and young people with HIV that this is also the case (Battles and Wiener 2002; Blasini et al. 2004; Ferris et al. 2007; Frink Sherman et al. 2000; Lesch et al. 2006; Wiener et al. 2006; 2007). Ferris and colleagues' study of 325 children in Romania also found significant physical health benefits from children being told their status, and concluded 'that knowledge of one's own HIV infection status is associated with delayed HIV disease progression' (Ferris et al. 2007:1092).

However, the overall picture of disclosure is not without some contradictions, and the assumption that disclosure just brings benefits is questioned by some research therefore mention should be made of the few studies that present evidence to the contrary. Some studies found increased problems amongst children who knew their status (Lester et al. 2002a, 2002b). For example, - New and colleagues (2003) found a higher degree of depression, anxiety, and withdrawal amongst those who knew their HIV status compared to those who did not. This study also found a slight increase in attention problems including aggression amongst those who knew their status. Although there is a large body of literature on HIV and disclosure it currently presents a mixed picture. However, there is mostly agreement that it is better to tell. As Wiener and colleagues conclude:

Based on the studies so far, there is no clear evidence that children who have experienced full disclosure have better or worse psychological outcomes than those who have not, despite the fact that secrets maintained in a family have been associated with unhealthy adjustment in other populations of children coping with chronic health conditions and despite

very strong clinical consensus that patients and their families do indeed benefit from disclosure. (Wiener et al. 2007b:162)

The benefits of disclosure to the child or young person may be well established in the literature however disclosure to other people outside the family is different and less well documented, but it is important to consider.

Disclosure to others

Previous research findings cite the fear of stigma as a major factor in discouraging young people from telling friends or family about their HIV status. Young people reported worrying consistently about others finding out their status, and identified risky situations, for example, people asking questions about their health, seeing them take medication or having to explain absences from school or not participating in social events (Bond et al 2000; Conway 2006; Melvin 2007; Miah 2004; Lewis 2001; Warwick 1999; Wiener et al. 2007b). Studies that highlight the stress engendered by the stigma of HIV also identify difficulties in keeping secrets (ibid.).

People with asymptomatic HIV often decide to maintain secrecy about their condition and engage in strategies such as 'passing' (Goffman 1963), by hiding their medication, fabricating reasons for medical appointments, avoiding potentially difficult questions or any risk of disclosure (Carricaburu and Pierret 1995; Madru 2003; Lewis 2001; Miah 2004; Conway 2006; Melvin 2003). Although HIV is a hidden stigma for most, managing social relationships and avoiding disclosure of an HIV status is identified as a source of stress (Alonzo and Reynolds 1995; Crandall and Coleman 2002; Michaud et al. 2009; Pierret 2000; Ragins 2008; Swendeman 2006; Wiener et al. 2007b).

Social interaction can be difficult because of the threat of potential discovery and this makes possessing a concealable stigma difficult for people to manage (Barroso and

Cope-Powell 2000; Pachankis 2007; Wiener et al. 2007b). Studies with HIV positive young people suggest that keeping family secrets can create barriers in their social relationships, and living with an illness that cannot be discussed with people they mix with every day presents difficulties for young people - problems resulting from keeping secrets have been reported frequently (Warwick et al. 1999; Lewis 2001; Melvin 2003; Bond et al. 2000). Saffer and colleagues note that the impact of keeping secrets is detrimental to the psychological well being of children; this led to a sense of shame about their condition (Saffer et al. 1979). Wiener and colleagues observed the emergence of shame:

Due to the stigma associated with AIDS, many HIV infected children have been asked to lie about their illness. As a result these children frequently develop a sense of shame about their disease and about what is happening to their bodies. (Wiener et al. 2007b:).

Children and young people find lying and keeping secrets about HIV difficult, particularly to friends and family (Lewis 2001; Michaud et al. 2009). Studies show that for most children and young people their peer networks are identified as an important source of support, and talking to friends is identified as a key coping strategy (Mellins 1994; Warwick et al. 1999; Murphy 2000; 2001; Lyon and D'Angelo 2006). Although the family is identified in studies as central in providing support for young people with HIV (Wiener et al. 2006; Lewis 2001; Lyon and D'Angelo 2006; Conway 2006; Miah 2004) friends are highly valued and the lack of friendships can be a source of distress for young people, thus being excluded from social networks can reinforce their isolation (Conway 2006; Warwick et al. 1999; Green and Smith 2004; Murphy et al. 2000; 2001; Lyon and D'Angelo 2006). Michaud and colleagues (2009) found that the attitudes of young people with HIV towards disclosure was related to those of the parents, particularly the mother. They observe:

Although foster/adoptive mothers would often encourage disclosure, biological parents, especially HIV positive mothers, insisted on not disclosing the adolescent's status for fear of stigma. (Michaud et al. 2009:356)

Few studies have explored the benefits or consequences of self-disclosure. However, Frink Sherman and colleagues found significant physical health benefit for those children who disclosed their status to a friend in their study of 64 children and caregivers. The childrens' CD4 count (measure of immunity) increased even when age and medication were controlled (Frink Sherman et al. 2000; Janoff-Bulman 1992). These support the findings of other studies with adults that show the positive health consequences of self-disclosure (Frink Sherman et al. 2000; Zea et al. 2005). A Romanian study concluded that 'knowledge of one's own HIV infection status is associated with delayed HIV disease progression' in children and young people (Ferris et al. 2007:1088). Other studies link the disclosure of personal or distressing information with improved psychological health (e.g. Greenberg and Stone 1992).

The literature on adults suggests that telling other people can be psychologically and physically beneficial. Disclosing traumatic events was found to increase coping mechanisms and support from others (Janoff-Bulman 1992), whereas suppressing distressing events and emotions is thought to increase stress, and over time, negatively affect health (Pennebaker 1985). The decision making process of disclosing HIV status involves risk assessment of possible rejection or alienation from social networks, and the loss of the ability to control subsequent disclosure and others telling (Armistead et al. 2001; Frink Sherman et al. 2000; Ostrom et al. 2006; Wiener et al. 2007b). In studies where young people have self-disclosed, such as Lee and colleagues' study of 350 young people between the ages of 13 and 23, young men (93%) were more likely to tell their friends than young women (79%); additionally, being told their status at an earlier age was significant in relation to disclosure to family. Studies which have examined self-

disclosure by HIV positive young people differ as to whether it is beneficial or not. However, there is some evidence of physical and psychological benefits and access to greater support. One of the most difficult disclosure decisions young people have to make is whether or not to tell a sexual partner and this is considered next.

Disclosure in sexual relationships

There is a growing interest in the study of the sexual behaviour of HIV positive young people (Wiener et al. 2007a; Fielden et al. 2006; Murphy et al. 2001). Young people with HIV view sexuality and sexual activity as much a part of their lives as their peers without HIV, (Valencia et al. 2000; Wiener et al. 2007a); and appear to have similar levels of sexual activity to those with other chronic disease, such as cystic fibrosis (Wiener et al. 2007a:475). Relationships present young people with practical and ethical decisions and dilemmas concerning disclosure and risk. Young people may develop sexual relationships within a peer group environment and therefore the risks and consequences of disclosure may be higher (Wiener et al. 2006; 2007a Melvin 2003). Disclosing an HIV status in a close or intimate relationships is a particularly difficult issue and causes anxiety for young people, as well as raising particular ethical issues (Bond et al. 2000; Miah 2004; Conway 2006; Lewis 2001; Lyon and D'Angelo 2006; Murphy et al. 2000, 2001; Wiener et al. 2007a).

There is no consistent pattern in young people disclosing their HIV status to a sexual partner. Lee and colleagues (1999) found that most young people (69%) told their sexual partners; having fewer sexual partners was significant in whether young people disclosed their HIV status to a partner (Lee et al. 1999). Young people with HIV are delaying the age of sexual activity (Wiener et al. 2007a), like young people with other chronic illness such as sickle cell and cystic fibrosis who report similar delays (Britto et al.1998; Cromer et al. 1990). However in the case of HIV, delayed sexual activity may be due to delayed puberty or delayed emotional maturity (Wiener et al. 2007a:476). Several studies report a delayed

onset of puberty for some young people perinatally infected (Buchaez et al. 2003; Nusbaum et al. 2003), and the reported decrease in sexual desire may be due to a variety of physiological and psychological influences, including tiredness and depression (Nusbaum et al. 2003).

Studies have demonstrated that some HIV positive young people are reporting practicing unprotected sex and engaging in 'risk taking behaviour'- as do their peers (Murphy et al. 2001; Melvin 2003; Wiener et al. 2006 2007a; Rotherham-Borus et al. 2001; Lewis 2001). Valencia and colleagues (2000) identify sexual risk taking in their review of high risk behaviour of adolescents with cystic fibrosis, haemophilia and HIV. Their findings that there was 'a substantial prevalence of sexual activity, but low level of knowledge and prevalence of contraceptive use in youths with chronic illness' were supported by Murphy and colleagues' subsequent study (Valencia et al. 2000; Murphy et al. 2001).

The tension between managing a relationship and the risk of transmission of the virus is a recurring theme in studies with HIV adults (Rhodes and Cusick 2000) and relationships are rarely, if ever, perceived to be free of risk (Rhodes and Cusick 2000). Unprotected sex is viewed as a powerful expression of commitment and love and Rhodes and Cusick found that the commitment to a shared destiny and exposure to risk was seen as a search for risk equality and a key feature of relationships survival (2000). Wiener and colleagues found that whilst negotiating safer sex is important to young people with HIV they find it difficult (2006). A subsequent study by Wiener and colleagues' (2007a) support previous research by Thomas and colleagues (2000), and Murphy et al. (2001) in recommending sexual health education and risk reduction programmes that include condom use, negotiation and disclosure of diagnosis to potential sexual partners (Wiener et al. 2007a; Conway 2006). The dilemmas of disclosure within sexual relationships add to the other stresses studies suggest young people with HIV experience. These are considered next.

2.7. Emotional disruption of HIV

Young people with HIV report feeling sad, depressed, lonely and isolated from family and friends thus the mental health of young people is a concern (Fielden et al. 2006; Murphy et al. 2000; Lyon and D'Angelo 2006; Riekert et al 1999; Wiener et al. 2006; 2007b). Young people report fear of unintended disclosure outside the family and a lack of opportunities for talking about HIV outside and within it. Not all members of the family may be aware of the HIV status of the child or young person, and young people perceive that talking about HIV upsets their parents, so they learn to keep silent (Lewis 2001; Melvin 2003, 2006; Bond et al. 2000). Living with uncertainty and the fear of unintended disclosure is problematic for those living with HIV (Fielden et al. 2006; Lewis 2001: 40; Wiener et al. 2006, 2007b; Lyon and D'Angelo 2006; Conway 2006). Lewis found the isolation and loneliness of the young people and their resignation to this loneliness particularly striking (2001:132). The social stigma and associated discrimination is reported by young people as being a key difficulty in coping with HIV (Melvin 2003; Miah 2004; Lewis 2001; Bond et al. 2000; Lyon and D'Angelo 2006); these studies reinforce the evidence of the social isolation that young people experience (Knight et al.1999; Lewis 2001).

People living with HIV are reported to experience significant amounts of mental health problems such as: mood disturbances, depression, anxiety, suicidal ideation and attempts and hopelessness (Gaughan et al. 2004; Havens et al. 2002; Kelly et al. 1998; Plattner and Meiring 2006; Brown et al. 2000; Whetten et al. 2008). A significant amount of research has explored mental health issues for adults with HIV but much less is known about young people (Lam et al. 2007). Adult studies in the US highlight the prevalence of depression in this group (Battles and Wiener 2002; Brown et al. 2000; Lam et al. 2007; Lyon and D'Angelo 2006; Mellins et al. 2002; Gaughan et al. 2004; Scharko 2006; Pao et al. 2000; Battles and Wiener 2002; Fielden et al. 2006). Lam and colleagues observe that 'HIV youth have mental health concerns in addition to the physical symptoms which characterise their illness' (2007:28) and suggest that this area requires further research.

This resonates with findings about children and young people with other life threatening illness (Lenton et al. 2001; Stuber 2003).

Studies of adults with HIV reveal a high incidence of psychiatric disorders (Scharko 2006), one study showing 60% of adults with depression, and a 25% incidence of anxiety disorder. Scharko (2006) suggests that children and adolescents may present with similar challenges, and Kilbourne and colleagues (2001) identify mental health problems as emerging with the increased survival of children and young people (Kilbourne et al. 2001). Wood and colleagues (2009) found that HIV positive young people are more likely to have cognitive or psychiatric problems than young people without HIV and Scharko concludes from the review of current studies that:

ADHD, anxiety and depression are all exceedingly common in HIV infected children and adolescents. Combining these findings with the many clinical observations of multiple behavioural problems seen strongly indicates that mental health issues are serious and frequently co-morbid for this population. (Scharko 2006:442).

Whilst Scharko's study has limitations in that it is difficult to establish a direct causal link between HIV and such problems, the literature highlights this area as one of growing concern. Pao and colleagues (2000) study of 34 HIV positive adolescents found that the majority (53%) of the young people in the study had a previous psychiatric disorder with 44% being treated for depression (Pao et al. 2000). As Wood and colleagues (2009) conclude from their recent study:

These data suggest that HIV infected adolescents, regardless of the severity of HIV disease, may require significant behavioural, psychiatric and educational support services as they transition into adulthood. (Wood et al. 2009:1865)

It appears from the research that where young people do not have adequate support or networks they become more prone to depression; the isolation imposed by HIV affects their opportunities to establish and sustain friendship networks. Unsurprisingly therefore, some studies link social support with less depression (Bond et al. 2000; Fielden et al. 2006; Green and Smith 2004; Lam et al. 2007; Mellins et al. 2002; Murphy et al. 2000; Miah 2004;). Improved mental health is reported where young people have better social support, which increases the sense of belonging and self worth (Lam et al. 2007; Mellins et al. 2002; Murphy et al. 2000).

The experience of the loss, or long term illness, of one or both, parents is also identified as a risk factor in depression, in part because it can lead to family disruption, separation and relationship breakdown (Lewis 2001; Lyon and D'Angelo 2006; Thorne et al. 2000). Overall, previous studies present a mixed picture of how young people cope with living with HIV; Murphy and colleagues (2000) found that for some young people, neither social support or adaptive coping seemed to affect or improve levels of depression. But as Brown and colleagues (2000) observe:

Children and adolescents with HIV experience more subjective distress than their uninfected peers, including dysphoria, hopelessness, preoccupation with their illness, and poor body image. Some adolescents with HIV report more sexual risk-taking behaviour and conduct of hyperactivity disorders. Many individuals with HIV have a history of negative life events, such as forced disclosure, loss of a parent or sibling due to AIDS, or abuse.(Brown et al.2000:86)

The literature shows that young people with HIV have to cope with a range of difficult events and circumstances, including the experience of multiple losses and bereavement. Expressions of grief are made more difficult because of the social stigma and secrecy

surrounding the cause of death (Fielden et al. 2006; Miah 2004; Wiener et al. 2006, 2007b; Murphy et al. 2000; Green and Smith 2004; Lyon and D'Angelo 2006). Bereavement is also accompanied by various difficulties for young people. For example, Battles and Wiener (2002) found that those young people who had lost a parent experienced more depression than those with HIV who had not experienced bereavement and those over 18 were less likely to have completed their education than their healthy peers. In one of the few studies of perinatally infected young people, Fielden and colleagues concluded that issues such as 'depression, bereavement, anxiety and suicide ideation are potential mental health concerns for HIV positive youth' (2006:1052); and other studies support their concerns (Battles and Wiener 2002; Murphy et al. 2000).

2.8. Making sense of illness

Most research exploring how people make sense of chronic illness or a terminal condition has focused on adults, although Woodgate's (1998) study of young people identified common themes and experiences across illnesses. She looked at young people with: diabetes, asthma, arthritis, Crohn's disease and ulcerative colitis and found that having a chronic illness made life more difficult for young people and required extra effort. She found they all experienced restriction, pain, and additional worries. She concluded:

Adolescents with different diagnoses experienced similar thoughts and feelings, which supports the belief that regardless of the type of illness, many individuals share the same concerns and problems. (Woodgate 1998:220).

Although HIV was not included in Woodgate's comparison groups and could arguably be seen as different, her observations help to shed light on young people's illness experiences.

Finding a reason and some meaning in illness appears to help people manage the disruption of chronic illness. Charmaz identifies several responses and models of coping with illness, such as: 'ignoring it, minimizing it, struggling against it, reconciling self to it, and embracing it' (1995:657). She proposes that an individual's response to illness is dependent upon how it impacts upon life and how much disruption is caused by the illness. Where HIV or other conditions become what Hughes (1945) and Goffman (1963) termed a 'master status' and the condition occupies a central part of a young person's life, the disruption to their life may be greater.

Charmaz (1995,1997) views the effects of illness as dynamic and continually changing as an individual's responses and adaptation also changes over time and circumstances. Making sense and finding meaning in having HIV involves reviewing and re-assessing one's life (Plattner and Meiring 2006). Barroso and Powell-Cope (2000:341) found that: 'people who searched for meaning were likely to view HIV as an opportunity to grow or to find new meaning in life'. They also found that accepting HIV/AIDS as a terminal illness whilst maintaining hope for a cure was difficult and 'that finding meaning translated into practical coping mechanisms to reduce uncertainty, cope with loss and face death' (2000:343). Barroso and Powell-Cope concluded that people who could find meaning in having HIV were more able to create a framework for coping with HIV and to establish relationships and 'human connections' (Barroso and Powell-Cope 2000:351). However those unable to do this struggled to find a framework within which to cope and to make meaningful relationships (Barroso and Powell-Cope 2000:351). It seems being able to make some sense of HIV and attach meaning may be helpful for individuals.

Most studies about making sense of having HIV have focused on adults (Schwartzberg 1993; Davies 1997). Schwartzberg (1993) identified three frameworks of meaning used by people with HIV: first a 'high' or 'conversion' growth discourse; second an 'irrelevant or normalizing' framework or discourse and third a 'shattered or loss' framework of meaning. Crossley (1999) highlighted the similarity of these discourses with studies of those with

chronic illness, such as Radley and Green (1987) who documented adjustment styles to chronic illness. Pantzou and colleagues (1998) identified three different ways individuals make sense of HIV. First a negative response, where HIV is viewed as destroying as well as interrupting a life course; second, HIV is viewed more positively in that although it interrupts and changes life, in some ways it also improves it, and thirdly nothing is changed in relation to life, either positively or negative (Pantzou et al. 1998; Pierret 2000).

Courtenay and colleagues (1998, 2000) identified a similar discourse, but they found individuals re-assessed their life and future and found a new perspective and appreciation of life that helped find meaning in HIV. They described this as a 'transformational perspective'. Spirituality and religious belief played a valuable role in people making sense of HIV (Courtenay et al. 1998:12, 2000). Other studies suggest being able to ascribe a religious rationale for suffering enables some individuals to find a purpose and justification for their condition (Baumgartner 2002; Plattner and Meiring 2006). Prayer has been identified by adults with HIV as beneficial (Ridge et al. 2007), and studies with young people with cancer have also reported similarly that a belief in God can provide support and reassurance for young people (Kyngas et al. 2001; Stewart 2003). Religion and spirituality were also identified by Atkins and Ahmed (2001) as an important way to find meaning and as a coping resource through which young people with Thalassaemia and Sickle Cell disease made sense of their condition.

Several studies have reported changes in perspective concerning life and death after a diagnosis of HIV and other life threatening conditions. For example, a study of trauma victims found individuals reinterpreted their traumatic experience which resulted in a re-ordering of life's priorities and 'most involve either a new found appreciation of life or a new found appreciation of oneself' (Janoff-Bulman 1992:135). Survivors reported that they did not take life for granted anymore and realised 'how precious life is' (Janoff-Bulman 1992:136). Participants also reflected on how the experience has made them stronger, more sensitive to others, more compassionate, caring, patient human beings

(Janoff-Bulman 1992:138). Courtenay and colleagues found that individuals with HIV came to similar conclusions to Janoff-Bulman's participants; these were characterised by empathy and altruism, particularly in relation to making a contribution, and being of service to others, viewing their role in life to now help other people (Courtenay et al.1999:13; 2000). They observed that 'HIV positive individuals interpret suffering to be less when it has meaning' (Courtenay et al. 1999:13). Baumeister (1991) found that people with an illness that may be terminal engage in activities and accomplishments that will have meaning after their death and therefore their life is not seen to be in vain.

The literature on finding meaning and making sense of HIV for children and young people demonstrates how individuals' confront issues of life and death, and face a possible limited life expectancy (Wiener et al. 2007; Lewis 2001; Murphy et al. 2000; Lyon and D'Angelo 2006). Studies have suggested that the knowledge of a restricted and possibly limited life span may affect future aspirations and goals, and lead young people to question the appropriateness of future plans and goals and whether these will be physically achievable (Hosek et al. 2002; Melvin 2003; Conway 2006; Lyon and D'Angelo 2006). The literature on how young people make sense of HIV illustrates the complex and demanding nature of the condition and the difficulties that young people face.

2.9. Summary

Previous studies have shown that young people may experience chronic illness differently to adults. Being young brings a different perspective to the experience of chronic illness as youth is a life stage where young people are dependent and have limited autonomy. If chronic illness is experienced as a disruptive biographical event it can interrupt and bring changes to a person's life and their view of self. The diagnosis of a life limiting illness creates 'critical' and 'fateful' moments (Thomson et al. 2002; Giddens 1991), and for young people these moments disrupt their biography further. The experience of chronic illness forces changes to identity and requires individuals to redefine themselves in light of

the changes illness brings. This is particularly difficult for young people as they are in the process of transition to adulthood. Their identity is in the process of being developed and a major disruptive event at this time has particular consequences. Identity comprises both an internal element of a person's personality as well as an external element that develops from participating in society. Young people's identity encompasses their aspirations and goals as well as their future identities. Chronic illness brings disruption to a young person's biography that is interrupted by 'critical moments' and results in a disrupted life course. The 'critical moment' of the diagnosis of an illness for a young person may affect the possibility of a 'normal' or 'choice' biography for them as their choices may be more limited. However, 'critical' moments may be experienced positively and provide an opportunity for self development and accelerate a young person's transition to adulthood.

The changes to a person's identity forced by the event of chronic illness may be differently experienced by young people than adults because of their youth. Youth is characterised as a time of transition where individuals have limited power and autonomy.

The concept of biographical disruption is helpful in understanding how chronic illness affects an individual's life as it is described as a process. This concept has not been extended to consider young people or been widely applied to those with generic conditions, or those born with health conditions. This concept was developed within an adult centred model of illness and has not been widely applied to children or young people. Biographical disruption may be experienced differently by those with previous illness or prior disruption in their lives. Young people may experience biographical disruption differently because of their life-stage and their lack of agency to control decisions that other people make. They live with the consequences of decisions that other people have taken on their behalf. Their experience may also be different because as young people they are in the process of transition to adulthood and dependent on others for care, protection and financial support. The disruption caused to biography by HIV may

be differently experienced than other long term conditions because of the particular stigma attached to HIV.

Previous studies demonstrate how HIV is viewed differently to other conditions because it is stigmatised. The public perception of HIV is founded on an historical discourse developed stigmatising sexual behaviour and fear of contagion. Metaphors of threat and plague are used in relation to HIV and are transferred to the individual who is thought to be responsible for their own infection and subsequently blamed. Although HIV is considered to be a concealable and invisible stigma, research suggests that hiding an HIV status is both stressful and emotionally demanding.

The literature shows the complexities of disclosure for young people who have been found to experience the same context awareness of their situation as adults when information about their health is withheld. Disclosure to young people and their subsequent disclosure to others is influenced by the fear of the stigma. However, there may be psychological benefits to young people in knowing their HIV status, enabling them make decisions and take control in uncertain situation. The experience of HIV appears to be no different from chronic illness and other diseases in that the individual seeks to find meaning and make sense of their condition in a number of ways.

Reviewing the literature on young people and HIV provides a context for this study and identifies some of the key issues. Previous studies point to particular concerns with this small group of young people and highlight the complexity of their situation. The following chapters explore the experiences of these young people and presents key themes however, it is first necessary to outline the methods used in this study.

Chapter 3

Research Design and Methodology

There are no right or wrong methods. There are only methods that are appropriate to your research topic. (Silverman 2005:112)

3.1.Introduction

This study aimed to explore and critically analyse the experiences of young people in the UK who have lived with HIV since birth. This is the first cohort of young people who are long term survivors of HIV and as such they represent a unique and sometimes forgotten population (Fielden et al. 2006; Gibb et al. 2003; Bell et al. 2003). My research is therefore one of the first qualitative studies to look at the experiences of this group in the UK and some time was taken to decide on the most appropriate research method. This chapter outlines how the research framework was developed and the process of the study. The chapter is organised into three sections, the first of which describes the background to the study and considers some of the issues in undertaking research with young people. Section two describes the framework and design of the research and data collection methods, whilst the final section contains details of the process of data analysis.

3.2. Background

The primary research question was:

- How do perinatally infected young people experience living with HIV?

The secondary research question was:

- How does HIV disrupt the biography of a young person with perinatally acquired HIV?

Young people in this study are defined as those between the ages of 13 and 24 years (United Nations 2006). Addressing any research with young people, particularly around a sensitive topic such as HIV, involves the consideration of certain ethical issues and these are considered next.

Researching sensitive topics

Undertaking research on sensitive topics as Lee (1993) observes, usually raises difficult methodological issues. Researching HIV is considered a sensitive area as it is likely to involve addressing personal issues and Lee talks about how the researcher:

May need to be more acutely aware of their ethical responsibility to research participants than would be the case with less sensitive topics.
(Lee 1993:2)

Part of the researcher's ethical responsibility is to consider the issues involved in doing research with young people who are seen as vulnerable.

Undertaking research with vulnerable young people

The young people in this study are seen as vulnerable by virtue of both their age and HIV status, and undertaking research with a group identified as 'vulnerable' requires particular consideration and additional safeguards need to be put in place (Alderson 1995, 2004; Fraser et al. 2004; Morrow and Richards 2002).

One of the main issues is the inherent power differential between researcher and young person, which, whilst it cannot be altered, can be lessened through the design and approach of the research. In the early stages of the research design I chose interviewing as my preferred approach, whether individual or group, because I wanted to record young people's experiences directly. Therefore I needed to ensure that the research environment was safe and supportive to allow young participants to have some control over the process, and for them to be able to refuse to participate without fear of repercussion (Fraser et al. 2004). In addition, the actual physical research environment needed to be suitable, particularly when considering interviewing as a potential method of data collection. It is also important to recognise that researcher responsibility extends beyond the actual participation of the young person in the research, to include for example, travel to and from the interview (Fraser et al. 2004). These issues were addressed in the design of the study, from how the interviews were conducted, to where they were held and how the participants travelled to and from the interviews.

Whilst the issue of informed consent is considered later in this chapter, a point worth highlighting is that, whilst young people may consent to being interviewed, they may give more information than they intended. Creating a relaxed and informal setting has to be balanced against keeping some structure that provides a boundary to young people sharing more than they would wish to. At the end of each interview I asked each participant if they were okay with what they had said and gave them an opportunity to comment. I am not sure if this genuinely provided an opportunity to re-consider what they had said in the interview but it provided a space for them to say something if they were really unhappy. This can be mitigated by obtaining consent as a continual process, rather than just a form that needs to be signed on one occasion, and by checking with the participants that they are happy with what they have said after the interview.

Finally, the issue of protection from harm is of particular relevance in research with children and young people (Alderson**refs). Researchers need to have strategies in place

to minimise potential harm that may arise from participating in research (Alderson 1995; Fraser et al. 2004; Morrow and Richards 2002). Where a researcher creates a safe space for young people to talk about their experiences there is always the possibility of unintended disclosure. It is important therefore that the limits of confidentiality are clear in relation to the disclosure of abuse or potential harm. This point was made clear to the young people in this study through written information and in discussion. It needs to be remembered that protection from harm includes protection from emotional harm and this study has the potential to upset and potentially distress participants as they recall their experiences. The issue of potential distress was considered when selecting the style and form of method and underpinned the reason for taking a sensitive and flexible approach to interviewing.

In this study a proactive approach was taken in regard to support and care for participants, which involved practical measures such as: making sure there was access to support; an up to date list of support agencies; the payment of travel expenses and ensuring that young people were accompanied. In addition to these practical measures, much thought was given to ensuring that this research was both safe and supportive for the young people participating.

3.3. Framework for the research

This study takes a qualitative approach and the reasons for this approach and the details are explored in this section. This section explains and provides some background to understand how the study, which comprised of a purposive sample that provides data from interviews with twenty-eight participants. I interviewed young people once, using semi-structured in-depth interviews based on an interview guide developed by me.

A qualitative approach

A qualitative approach has been shown to be effective in looking at a range of experiences, meanings and attitudes across different contexts (Bryman 2004; Grinyer 2007; Silverman 2004). A qualitative approach seemed to be the most appropriate means of researching the lives of young people because listening and reflecting the significance of what people have to say about their lives has a long and respected history in social science research and forms an important element in qualitative research (Silverman 2001). This approach has also been shown to be appropriate to document the personal accounts of adults living with HIV (Barroso and Cope 2000; Power 1998), and though my study focuses on the experiences of young people, a qualitative approach is still seen as the most appropriate.

Researching the 'voice' of young people: the research relationship

In research that seeks to privilege the 'voice' of participants, it is important to acknowledge that the production of the voice involves interaction and a relationship between the researcher and the researched (Silverman 2001). It also involves the interpretation of the account created jointly by the participant and researcher. The influence of the researcher affects all aspects of the research process, from the choice of topic, through to the interviews and analysis. The shape of the interview and the questions asked by the researcher generates the subsequent data. Silverman reminds us that there are dangers in listening to the 'voice' uncritically and without considering the broader context in which the voice is placed (Silverman 2001), as this risks ignoring the influence of the researcher and research relationship. As I have worked within this field for many years as both a practitioner and adviser to organisations working with young people with HIV, I was aware that my familiarity with the issues may influence the collection and interpretation of the data, therefore it was important to listen to participants' voices and remain focused and led by the young people's words. As Coffey (1999) suggests, this can be countered by reflecting and reviewing one's own position and place and identity during the research to

heighten one's own awareness. This was done in part through keeping field notes and a reflective account of the interviews and the research process.

This study involved establishing a short but intense relationship with participants as they recounted their very personal experiences of living with HIV in an interview. One of the main drivers informing the choice of methodology for this study was the design of a flexible approach that allowed participants to have some control. Whatever approach used must enable the young people to talk freely about their experiences, and by planning a broad and open structure to the interviews, I anticipated that this would offer more flexibility and control to participants (Gubrium and Holstein 2002; Rubin and Rubin 2005; Silverman 2001).

Recording the direct experiences of young people was central to this study because studies indicate that young people tend to have their views and opinions mediated through adults, usually through their parents or carers (Conway 2006; Morrow and Richards 2002), and as Fraser et al. observe 'historically, research has marginalised the 'voice' of young people' (2004:177). Therefore it seemed appropriate to consider a method that focused on hearing young peoples' voices, and this led to considering interviews.

Interviews as a method are not without their critics; some have criticised the use of material collected in interviews as data, suggesting that participants would not have talked about the research topic in the way they did without the researcher's intervention, in essence therefore, the data has actually been produced by the method (Potter and Hepburn 2005). Silverman defends this accusation by suggesting that interviews are a form of social interaction and talk is a normal part of life in Western societies (Silverman 2001). Many would agree that interviews are culturally situated, but can also be seen as an extension of 'naturally occurring talk' and as Taylor (2001) reminds us, people may agree to participate in certain research because it reflects a particular interest or experience and this point may well be relevant for this study. Some interviews may

represent well rehearsed 'public' accounts, but the talk produced in the interview can be analysed as part of a wider experience of participants. Interviews can be seen both as 'true' accounts as well as situated narratives because interviews are the product of talk within the experience and context of the participant (Silverman 2001).

Qualitative individual interview was the method of choice for this study for several reasons: firstly, because the topic to be studied is both sensitive and personal, and secondly, because as a researcher it is an approach that felt comfortable and familiar when thinking about the best way to hear young peoples' accounts of living with HIV. Finally, and most importantly, it seemed to be the 'best fit' for this study. In trying to decide on the most appropriate method for researching this area several other approaches were considered and these are discussed next.

Considering other approaches

Whilst interviewing was always the preferred method when considering approaches to this study, the form was the subject of much thought and discussion. Focus groups were considered as enabling the generation of a range of information and experiences in a setting that may be more supportive for young people than one to one interviews. Focus groups were rejected as a method, as they did not seem to provide the privacy necessary or a safe enough space for participants to talk about personal experiences. Paired interviews were also considered, informed by research carried out in other sensitive areas (Eder and Fingerson 2003). Children and young people reported finding this process easier, and less exposing when accompanied by a friend. This approach was rejected in part because of the practicalities of the small number of potential participants being able to identify a partner to join them in the interview, but, essentially because the focus of this research is on the individual account. Ritchie and Lewis identify this individual focus as one of the key features of the individual interview:

One of the key features is their ability to provide an undiluted focus on the individual. They provide an opportunity for detailed investigation of people's personal perspectives, for in-depth understanding of the personal context within which the research phenomena are located, and for very detailed subject coverage. (Ritchie and Lewis 2003:36)

In essence, it is that 'undiluted focus' that is possible in the one to one interview that seemed to be the 'best fit' for this study. The individual approach seemed to mirror the fact that each participant has their own voice to be heard, and their own unique story to tell. How able each young person is to tell their own story is limited by their ability, desire or confidence to tell their story. Where a young person is unable to articulate their story or finds it hard to talk, it does not mean they have no story to tell. As Thomson et al. observe this is the difference between 'the life lived as opposed to the life told' (2002). Thus, despite some concerns over whether young people would feel confident enough to be interviewed alone, it was decided that this approach would be used.

3.4. Design of the study

As the study was designed to analyse the experiences of young people living with HIV it was important to select a sample that represented the widest possible range of young people born with HIV and living in the UK. An HIV service in a London teaching Hospital was selected, in part, for pragmatic reasons as I had a professional link with the hospital but, not with the clinic. It also offered the opportunity to access young people with a wide range of health experiences related to HIV, including those with more complex health problems.

The Hospital represents a centre of excellence for HIV in the UK and as such children and young people are referred from across the country. The hospital service includes one of the first HIV Family clinics where both children and families are seen, and an adolescent

clinic to which young people are transferred to once they reach the age of sixteen. There was the option of accessing young people through several different voluntary organisations but I felt this would be a self-selected group who represented the more able and self-confident young people who were able to access and take up support outside the hospital. I was keen to carry out this study within a hospital setting because the range of young people accessed was wider. Those who attend hospital sometimes do not go anywhere else and it enabled me to access young people that had I undertaken the study in a voluntary organisation would not.

Young people who attend the hospital have a range of health issues connected to their diagnosis; some are quite well, attending only as outpatients; whilst others have severely compromised health with recurrent infections, illness and regular hospitalisations. By choosing to undertake the research within this setting opportunity was afforded to access young people with very differing experiences of living with HIV. This included young people who were terminally ill. It also provided access to young people that do not use support organisations and only attend the hospital.

Ethics

A year before formal ethical approval was sought I met regularly with nurses, doctors, psychologists and administrators to discuss the study and their potential involvement. I needed their support and also their acceptance of both the research and my competence to undertake it before I could consider the next stage. It was with the agreement and support of the medical staff that I began the formal process of gaining ethical approval.

Ethical approval was required from The Open University Human Participants and Materials Ethics Committee, the NHS Hospital Trust and several Internal Research Governance Committees. Applying for ethical approval was a complex and lengthy process, but proved helpful in elucidating the key concerns of those in the wider research community. The main issues raised in the OU and NHS processes were about consent

and protection. The issue of consent was raised by the OU committee in relation to age and competence of those under the age of sixteen years. Their concern was about what would happen in a situation where a young person under the age of sixteen wanted to participate but the parent did not agree. Gillick competency (Fraser et al. 2004:48) was discussed along with the right of the child to participate and it was agreed that where a young person under sixteen wanted to participate they would need to seek parental approval and make their decision together with their parent. In the event, no parent of a young person under sixteen refused to consent to their child participating.

The NHS Ethics Committee raised the issue of protection from harm. Despite the research protocol including a comprehensive child protection policy, the concern focused on the potential risk of emotional harm to participants. Several individuals on the committee were concerned that participating in this study would upset young people, particularly younger people and expose them to unnecessary distress. This research was viewed as sensitive and the young people particularly vulnerable and in need of a greater degree of protection. Following the raising of this I met with two members of the NHS Committee to discuss their concerns. I explained that exploring young people's experiences of living with HIV is likely to raise some distressing issues but that does not mean that they are unwilling to talk about their experiences. I reiterated that the important issue is to ensure young people actually give informed consent that the interviews are conducted in a sensitive manner, and that young people are allowed to have some genuine control of their interview situation.

Support resources had already been identified and put in place for participants in that I had arranged for counselling and psychological support to be available from a voluntary organisation as well as agreement from the hospital for access to psychological services if necessary. However, a wider geographical range of support resources was identified outside London and subsequently the research was approved. Permission was given to interview young people from the age of thirteen upwards. Following ethics committee

approval I attended two internal NHS committees: a Research Governance Committee and the HIV Medical Group to present my study before final agreement was given. The process for ethical approval took over five months to complete. (Ethical Approval papers can be found in Appendix 1).

Criminal Records Bureau Check and Data Protection

An Enhanced Criminal Records Bureau check was required to undertake this research given that there was access to vulnerable young people. In addition, registration with Data Protection was required.

Inclusion criteria

The inclusion criteria were decided upon by considering three key issues: first, the age of young people - participants needed to be able to talk about their diagnosis therefore it was important that they had known about their diagnosis for at least one year to have had some time to adjust to their diagnosis: second, they needed to be medically defined as perinatally infected - all the participants were medically defined as having perinatally acquired HIV infection, however there were two young people adopted from Romania who lived in families where the parents' status was unknown: third, they needed to have been in the hospital service for at least six months. This was important because they needed to have been assessed by the medical team and settled into the hospital clinic routine before they were asked to participate in the study.

Participants therefore needed to fulfil the following criteria in order to participate in the study:

- Be between the ages of 13 and 24 years

- Be medically defined as perinatally infected with HIV
- Have been aware of their diagnosis for at least one year prior to the study and be willing to talk about HIV to the researcher.
- To have been accessing the hospital service for at least 6 months prior to the interview.

Interview guide

Whilst the interviews were designed to ask broad, open-ended questions and were semi-structured, an interview guide was designed to ensure consistency and to ensure that all areas identified were covered in the interviews. The interviews covered areas such as: family, relationships, health, school, work, and the future. (Topic guide and questions can be found in Appendix 3).

Age range

The age range selected initially was between 13 years and 24 years, reflecting the United Nations definition of a young person (UN. 2006). This age range was also chosen in part because of the age of disclosure of diagnosis to young people. Research suggests that in the UK young people begin to be told about their diagnosis at around 12 years (Conway 2006; Melvin 2006; Miah 2004). However, as the study progressed it became clear that recruiting younger people to the study, those between 13 and 14 years, was more difficult because some of these young people had not known their diagnosis for the one year inclusion criteria, and some parents were reluctant for their children to participate. Given the small number of potential participants and the smaller number of younger people eligible to participate, a decision was made to focus on young people between the ages of 15 and 24 years.

Sample size

The planned sample size in this study was originally 25 participants, but ultimately 28 participants were interviewed; the pilot study comprised 3 participants and the main study 25 participants. An opportunity to interview the additional 3 participants from this small group was presented and so interviews were carried out. After interviewing 28 participants I felt I had reached data 'saturation' where similar themes and issues were being raised consistently by the young people. I had intended to recruit as far as possible an equal distribution between male and female, but this proved too difficult as there are fewer young men having survived HIV beyond childhood than young women (Melvin 2006). This is reflected in the clinic population and in other studies of this population in other countries (Fernet et al. 2007; Michaud et al. 2009). The study therefore comprised 10 male and 18 female participants. The sample was drawn from one hospital where the ethnic mix of young people with HIV was representative of the spread of HIV infection in London, with over 60% of participants being born outside the UK, and over 50% of these were born in the following African countries: Zambia, Uganda, Zimbabwe, Ghana, Kenya, Djibouti. The remainder of participants were born in the UK. Twenty-four (86%) participants had one or both parents born outside the UK, nearly 70% being from African countries. The ethnic mix of the sample is similar to the pattern and distribution of HIV infection in the United Kingdom (Brown et al. 2000; Conway 2006; Gibb et al 2003; Miah 2004).

Written information

Participants and their parents were given written information about the study to enable them to make an informed decision about participation. The information sheets were written for parents, doctors and the young people, separate information being written for those under and those over the age of sixteen. The written information for participants was piloted with some young people in the same age range for comment on how clear it

was to understand. These young people were from the same voluntary organisation where the pilot study was carried out and were not included in the main study. Designing accessible and readable information for young people with a range of educational levels was important. The information sheet explained the reasons for the research, why it was being done; what it hoped to achieve, and more importantly, the participant's rights in the process, and their right to withdraw from the research at any stage without repercussion (Silverman 2004; Stanley and Sieber 1992). Young people were also offered feedback from the interviews once the study had been completed in the form of a summary report of the general findings. Participants were assured confidentiality and anonymity and asked to sign a consent form giving permission for extracts from the interviews to be used in my thesis, future articles and books. Those young people under the age of 16 years required parental consent. (Information sheets and consent forms can be found in Appendix 2)

Negotiating access

When undertaking research in settings such as the NHS access usually needs to be negotiated through individuals or groups who manage the services. Whilst these gatekeepers have no legal rights in respect of the person's decision to participate in research, they may control access to participants and they may have legal responsibility for a person's well being in that setting (Masson 2004; Wiles et al. 2005). They also have the power to influence the way participants are informed about the study and may influence a person's willingness to participate (Wiles et al. 2005).

Because of these difficulties there is a danger in research with young people that in negotiating access the researcher can focus attention on gaining access from the adult gatekeepers or parent, whose permission and co-operation are firstly required before access to the young people can be considered. The difficulty in accessing this group of young people has been documented in several studies (Cree et al. 2002; Lee 1993) that show that these young people appear to be well protected by a range of gatekeepers and structures (Heath et al. 2006). As Lee notes:

Researching sensitive topics raises difficult methodological issues and access is often problematic. (Lee 1993:2)

Gaining access to participants in this study was made easier by the existence of a professional relationship between myself and the consultant clinical psychologist, and my previous professional experience of working in HIV. There is debate as to whether researchers should have knowledge of the topic because of the possible bias it may bring to data collection or analysis, therefore my prior professional experience is acknowledged within this research as an important source of additional data enriching data analysis (Strauss and Corbin 1998a), rather than an influence which distorts the researcher's ability to collect and analyse the words of participants (Glaser 1992). My prior knowledge was acknowledged as a foundation on which this study was based.

In order to establish good working relationships with the medical staff regular meetings were held in the year preceding fieldwork where I presented details of the proposed study and supplied a briefing paper. The support and co-operation of the staff within both the family clinic and the adolescent clinic were essential in securing access to this group. Maintaining the relationships within the hospital throughout the life of the research is an important element and one that can greatly affect the progress of the research, particularly in relation to the recruitment of participants.

Pilot study

The aim of the pilot study was to confirm that the research method selected was the most appropriate for this study and to see if there was any need to reconsider the proposed methodology. The pilot study took longer to complete than anticipated due to difficulties in identifying and accessing young people. Several voluntary sector agencies were approached and two young people were identified as potential participants. However,

when I met with the young people to discuss the study, it became apparent that they were in particularly vulnerable circumstances and their participation in the study was not appropriate. Their circumstances demonstrated the complex lives and histories of many young people who live with HIV and highlights a tension in undertaking research with this group. As a researcher trying to secure interviews with those from a very small group there is a tendency to be over keen as one is acutely aware of how difficult it is to recruit participants. The details of the two young people's story served to remind me of the reality of what I was asking young people to share with me in this study.

The two potential participants were sisters, fourteen and sixteen years old who were in foster care and had come quite recently to the UK as unaccompanied minors and refugees. They had been through very traumatic and distressing experiences in Africa, and had lost most of their family in violent death, and as we began to discuss the research they found recalling some of their experiences very difficult. During the meeting it became clear that participating in this study may have created further distress for them and so they chose not to participate. Whilst this delayed the pilot study, it seemed the appropriate decision as they had experienced substantial trauma and the interview process may have added to their distress. However, three young people (1 woman and 2 men) were eventually found identified through other voluntary organisations and pilot interviews were conducted, two in London and one in Northern England.

The pilot study confirmed several issues and highlighted potential difficulties that contributed to the final design and methodology of the main study. One of the key issues arising from the pilot study was the importance of having a dialogue with young people in discussing the research and gaining informed consent. As a researcher, the focus can sometimes be on obtaining consent from the adult gatekeepers, and the relief at securing adult consent can deflect attention from the important issue of consent from the young people themselves. On reflection, this happened in the first of the pilot interviews. The pilot study also highlighted the need to talk through the research with participants because

one cannot assume that all young people are literate, and they are unlikely to disclose this (Alderson 1995, 2004). In relation to the interviews, a semi-structured approach worked well in directing the young people through the topic guide. Adhering to the topic guide was initially a challenge, as the young people talked about many other issues, but the pilot study taught me to learn how to guide the interview without affecting the flow of talk.

Data from the pilot study is used in the thesis as the research method was not altered as a result of the pilot study which confirmed the appropriateness of the method and emphasised the importance of the research relationship. Following the completion of the pilot study fieldwork commenced.

Fieldwork

Fieldwork began in May 2007 and the last interview was completed in February 2008.

The following section describes the environment of the adolescent clinic to give context and some background to the interviews.

The Adolescent Clinic

The adolescent clinic is one of the few in the UK and was established in response to the number of young people that had dropped out of the adult service once they had transferred from the family clinic to the adult clinic (Miles et al. 2004). Whilst many young people have been known to the hospital service for some years, others transfer from hospitals elsewhere in the UK. Most young people attend the clinic every three months, but this varies dependent on their health status and medical needs. The clinic is housed in a modern medical building alongside a centre for medical trials and is staffed by a small team.

Clinic staff

The staff at the clinic includes a Paediatric HIV senior registrar, a clinical nurse specialist, staff nurse and other staff who are consulted as necessary, including a psychologist (adult), dietician, and pharmacist. There are three receptionists who alternate clinics, and who book appointments. When fieldwork commenced, the clinic was held every two weeks and extended to being held weekly in 2008 when two doctors staffed the weekly clinic. The staff team is predominantly female and white, with the exception of a male nurse and psychologist.

The clinic environment

The clinic is a shared resource and alongside the adolescent clinic there are two doctors who see booked adult patients with HIV. In the clinic there is a reception area and several consulting rooms, a counselling room and a clinical examination room. There are several NHS easy chairs and tables with magazines for young people which are put out at the beginning of the clinic. There are four to five young people seen in each clinic which runs from 1pm to 7pm. During my fieldwork there were a small number of young people who failed to turn up for appointments but most attend, and those that are accompanied come with a friend, partner or parent. There was a sense of informality about the clinic and the staff appeared welcoming and friendly towards the young people. The relationships between the medical staff and young people appeared very positive with the staff displaying clear commitment to the young people and their health and care. There is a pre-clinic staff meeting before each clinic to which I was welcomed, where the young people attending the clinic are discussed by the team prior to their appointment.

Relationships with the clinic staff

Establishing good working relationships with the medical team was important to the research as they were the key adult gatekeepers with access to the young people. The doctors and clinical nurses were committed to the research which they suggested was

important. Regular meetings were held with the medical team before the commencement of the study and this helped establish the relationships prior to the fieldwork. On reflection, I sensed that these relationships were helped by demonstrating an understanding of some of the issues for young people with HIV through discussions, and a formal presentation of my planned research. What also helped was the relationship being brokered by the consultant psychologist who promoted the research as being in a 'safe pair of hands'.

Being seen as a 'safe pair of hands' at times felt uncomfortable and created a tension as to whether I was an 'insider' or 'outsider' (Olson 1977). Whilst I was welcomed into the pre clinic medical meetings, staff were keen to engage me in ascertaining my views and comments on young people that I had interviewed. Staff wanted to know what the young people had said in the interviews; in part they were concerned about their well being, but they were also concerned that they were viewed positively by the young people. This situation was managed by being clear about my role and boundaries as a researcher but the situation highlighted a tension that exists in undertaking research in such a practice setting. On reflection, this tension seemed more acute perhaps because I had been a practitioner previously. This lessened over time as my role as a researcher became more established within the clinic and as I became more comfortable and confident in the transition from practitioner to researcher.

Recruiting participants

I began recruiting participants to the study firstly through the adolescent clinic where young people were over the age of sixteen. I planned to recruit younger participants at a later stage. It soon became clear that access to the older end of the age range was easier, in part, because they could make the decision to participate themselves, without necessary reference to their parents, but also because there were fewer and less complex 'gatekeepers' in the adolescent clinic than in the family clinic.

Information about the study was given to all staff. However the doctors and clinical nurse specialist were key in negotiating access to potential study participants. It was agreed that they would talk to the young people first and if they expressed an interest in the study introduce them to me to discuss the research further and answer any questions. If appropriate an interview would then be arranged or contact numbers exchanged to enable arrangements to be made for an interview.

As I attended the clinic on a more regular basis, the team identified young people that may be interested in participating at the pre-clinic meeting. There were several young people excluded from the study by the medical staff, due to severe health problems, including mental health issues. Only one young person declined to participate in the study, saying that her mother did not want her to do so. Where I had contact with parents, most were keen for their child to take part in the study and others were happy for their child to make his/her own decision.

Recruitment of young people is a challenge, as there are many competing demands on their time, and consequently I had to be very flexible and patient and be prepared to spend much time waiting around. In addition to recruiting from the Adolescent clinic, participants were recruited from the Family clinic (where children attend up until the age of sixteen) where the administrator, rather than the medical staff identified potential participants. Recruitment became much easier once the young people and staff became more familiar with the study and my regular presence at the clinic, and the last two months of fieldwork yielded as many interviews as the first four months.

Arranging interviews

At the start of the study most interviews were arranged by personal contact in the adolescent clinic but, as the study progressed more interviews were arranged by mobile telephone and text. Each interview was brokered by someone from the hospital, the trust

in the relationship with the hospital appeared to be passed on to me, as the researcher. Without this brokerage access to participants would have been more difficult.

Mobile phones and texts were the main source of communication with the young people. Arranging the time and place of interview was quite difficult, as some cancelled at the last minute, or forgot and these practical issues served as a reminder of the reality of research with young people. I learnt that when interviews were arranged I needed to text several reminders to confirm the arrangements. Young people have busy lives and there was a need to 'fit in' with the demands of school, college or work. I had to become more flexible, responsive and understanding of these competing demands and, as young people tend to be more spontaneous than adults, I had to adjust my expectations in order to complete the interviews.

Reflecting on the process, these young people were a group that appeared keen to be interviewed; they seemed interested and reliable once arrangements were made, but, arrangements had to be flexible and at times made at short notice. It was not possible to plan too far ahead for the participants and most wanted to be interviewed within days of contact rather than weeks. This may be a similar pattern to adults but in order to secure interviews with young people I needed to be very flexible and fit around their lives.

Giving information about the study and informed consent

Giving succinct information about the study was, surprisingly, more of a challenge than I had anticipated. There are tensions in the balance between wanting to secure an interview and being aware of not 'persuading' a young person to participate. The written information given to potential participants has to be brief, concise and convincing. Likewise in discussing the research with the young person, the information had to be the same. Most of the young people wanted to know why I wanted to do the research, and what the purpose of the study was. The information given usually included some details

about my previous work with young people with HIV, in part to address the issue of legitimacy, but on reflection it was also to make a personal connection with them. The questions most asked about the study focused on either confidentiality and anonymity, or the purpose of the research. Several expressed what could be interpreted as 'altruistic' motives; they spoke of being prepared to take part to help others or in the hope of changing attitudes, 'making a difference' and having their story heard as a 'legacy'.

In the discussions with potential participants, the right to withdraw from the research at anytime was always made very clear. Ensuring genuine 'informed consent', participants were asked throughout the interview if they were happy to continue and at the end of the interview if they were happy for the interview to be used (Wiles et al. 2005). In one interview where a young person became upset I made the decision to switch the tape recorder off and sought her permission to re-start recording when she agreed. Offering young people an easy way to stop the interview or decline to participate is essential in research with young people, and the environment created by the researcher and the research relationship are central to this being a reality rather than wishful thinking. Making it safe and easy to say 'No' is important and more difficult than persuading a young person to participate.

The next section discusses the interview process.

The interviews

Twenty eight participants were interviewed for this study and the majority of the interviews took place in the adolescent (15) or family clinic (5) where the young people chose to be interviewed. Others took place on a hospital ward (4), (2) in voluntary organisation premises and (2) in the home of the young person. The place of interview did make a difference, for example two young people were interviewed in their home and I met their parent/carer. Although I interviewed these two young people alone, the parent and carer

were also at home and their presence added a different dimension. In one case a grandmother kept bringing in tea and at the beginning of the interview she sat outside the door of the 'interview' room until the participant asked her to leave in order not to be overheard. The grandmother returned after the interview and presented me with vegetables from her allotment and thanked me for doing the research. The interviews in a participant's home seemed more intimate because I had been invited into the young person's home, and the power differential seemed less weighted in my favour. The familiar surroundings may have relaxed the young person more and given a different dimension to the interview being away from the hospital. However, most interviews were held in the hospital, the majority in a private room in the clinic, and three young people were interviewed in side rooms of a ward when they were in-patients.

The interviews were one to one; the young people were interviewed alone, and they were digitally recorded with their permission. At the start of the interview the purpose of the research was outlined, and the information sheet and consent forms explained and talked through with the young person in a friendly and relaxed manner. Participants were given the opportunity to ask any questions about the research before the interview began. They were also told that should they become upset or wanted to stop the interview they could indicate to switch off the tape recorder at anytime. Participants were assured confidentiality and anonymity and were asked to sign a consent form. Parental consent was required from those under 16 years. The interviews lasted between one and three hours.

An informal, responsive, and relaxed interview technique was adopted, aiming to create a safe and trusting environment where the young person felt able to talk. The approach was purposefully relaxed as I was aware of the need to minimise the power imbalance between the young person and myself as the interviewer through the use of words and body language. Rubin and Rubin (2005) talk about a responsive interviewing approach that acknowledges that both the interviewer and interviewee are human, and that they

both form a relationship within the interview. The goal of this interview technique is to generate depth of understanding, and allows for flexibility throughout the process (Rubin and Rubin 2005). It is this approach that was followed in the interviews.

Communicating to the participants that I understood some of the difficult and sensitive issues relating to HIV appeared to help participants relax and to give them reassurance that the interview was indeed a safe space in which to talk. My knowledge of HIV and the concerns of young people enabled me to demonstrate my understanding and acceptance of their situation. Previous experience of working with young people with HIV and interviewing experience as social worker, nurse and counsellor helped my confidence to develop in the interviews. The topic guide and interview questions were followed in all interviews, but what the participant decided to share and talk about directed the interview and individuals decided how they spoke and for how long. Using a responsive approach in the interviews enabled me to probe and reflect on participants' responses, and to ask such questions as how, and why, in relation to expressions of feeling and explanation (Rubin and Rubin 2005). Using this approach the researcher needs to be adaptable and be able to pursue a new theme or insight as he/she listens to what is being said, and to feel comfortable in changing direction in the interview. Rubin and Rubin add a cautionary note that in this approach the interviewer needs to be mindful of not imposing their views on the interviewee (Rubin and Rubin 2005:37) and I was conscious of this potential pitfall throughout the interview.

Responding to reflections and statements involved me in probing and asking for clarity about some of the responses from the participants. This was done in a reflective and questioning style to enable greater depth of understanding to be ascertained. Influenced by a grounded theory approach (Glaser and Strauss 1967), each interview highlighted further areas for exploration and influenced how I conducted the following interviews. How I conducted the interviews did change over time, and these changes were informed by

previous interviews and what I was hearing; I adapted how I conducted the interviews although I always covered the same topic areas.

Talking about sensitive and very personal issues is a challenge for interviewers and it was important to guide the young people through their stories in a way that supported them and did not cause distress. I tried to ensure that questions towards the end of the interview were lighter in tone and positive as opposed to a focus on the more difficult emotional issues, such as death, loss and grief. In some interviews this was not always possible, particularly with those who were facing severe health problems. The content of the interviews for most of participants contained some distressing and sad reflections, and it was important to manage and contain these issues with sensitivity and care (Bluebond-Langner 1978). The feedback from the participants was that the interviews were really helpful and for some had been the first time they had talked about these issues with anyone; several said they found them an enjoyable experience and were surprised at how talking had made them feel better. These were untold stories.

Whilst the interviews were thoroughly engaging, they were also intense, and, although not unexpected, the emotional content of the subject and the response of the young people was a powerful combination. An additional issue was that of legacy, as well as recording their experiences, several participants with severely compromised health spoke about telling their story as a legacy to help others, which at times, as others have reflected, placed a heavy responsibility on me as a researcher (Bluebond-Langner 1978).

After the interviews

After being interviewed, all the young people were given details of support networks and contacts. They were also given a ten pound mobile phone top up voucher or token after the interview as a thank you for their time. Several young people declined the voucher, saying they were happy to take part anyway and others had to be encouraged to accept a

voucher. After each interview I sent a text to each participant or wrote a card to those who were happy for me to send details of their mobile phone 'top up' voucher home, to thank them for taking part, and to ensure they were safe and not distressed. The young people appeared to respond positively to taking part in the study and on reflection I was surprised at this response. Several made independent contact after the interview to say thank you and say that they found the interview really helpful. Participants were open and able to talk freely in the interviews about a range of very personal and at times distressing issues. Being given the opportunity and space to talk to an 'outsider' it seems for some was helpful.

This research was emotionally demanding for me as a researcher and some interviews were much more distressing than others. I found writing field notes after each interview helped me to de-brief but it was necessary to talk to my supervisors and third party monitor at times. However familiar I was with the stories of these young people, as a researcher I was not in a position to respond or do anything to 'make it better', which my previous roles had afforded me. Adjusting to this position was part of my journey from practitioner to researcher.

3.5. Analysis of the data

A challenge to using qualitative methods is how the range and complexity of data generated is handled and analysed. Identifying and drawing out the key issues from this large amount of complex data is a challenge, but in considering the complexities of the experiences of young people, qualitative methods and data are best suited to consider the issues that they themselves identify as significant (Maluccio and Anderson 2000). Although this study did not use narrative analysis as a method, the word 'narrative' is used to describe the accounts young people gave and the explanations of their positioning.

Thematic analysis was used in the study together with a data driven inductive approach, allowing themes to emerge directly from the data using inductive coding. Thematic analysis is a search for themes that emerge from the data as being important to the description of the experience (Daly et al. 1997). The process involves the identification of themes through 'careful reading and re-reading of the data' (Rice and Ezzy 1999:258). It involves looking for pattern recognition within the data, where emerging themes become the categories for analysis. My analysis also included developing codes from the data using a 'data driven inductive approach' (Boyatzis 1998).

All the interviews were audio taped and transcribed verbatim and field notes were also transcribed. The transcripts included recordings of silences, pauses and emotions such as laughter and tears and stalling words such as 'umms' and 'aah'; they also recorded interruptions such as mobile phones ringing or participants receiving texts which were helpful in prompting both my memory of the interview and helping my interpretation of meaning. I transcribed half the interviews and the remainder were transcribed by a professional transcriber recommended by The Open University. Transcription involved listening and transcribing verbatim and re-listening to check the accuracy of the transcript. Using a professional transcriber proved helpful, but I felt I had to offer some support, such as asking if she was alright after transcribing particularly difficult interviews and allow her time to talk about it if necessary, given the nature of the interviews. Once transcribed, the interviews were re-listened to and checked over twice to ensure accuracy. Having some of the interviews transcribed saved time, but it did not lessen the task. Analysis began as Taylor and Littleton suggest:

Analysis and interpretation are not based on one single interview but on the immersion in the larger body of data and the search for patterns across it. (Taylor and Littleton 2006:14).

Data analysis was conducted on several levels, informed by different assumptions, but began by an immersion in the data, to discover what it was saying. I began this process after the first interview by reviewing what I had learnt and what issues may need to be followed up in the next interviews. This approach allows on-going analysis and enables one to modify and follow up on emerging ideas (Rubin and Rubin 2005:37). The analysis was thematic and themes were identified by careful reading and re-reading the transcripts; focusing on identifiable themes and patterns in the interviews (Aronson 1994). A theme is defined by Boyatzis as 'a pattern in the information that at minimum describes and organises the possible observations and at a maximum interprets aspects of the experience' (1998:161). Transcripts were coded, using an open and inductive approach in order to be data driven. As Boyatzis (1998) observes a 'good code' is one that captures the qualitative richness of the data. Coding enables the data to be organised to identify and develop themes from them. The dominant themes I identified from the interviews then formed the basis for the data chapters in the thesis.

The process of analysis

Initially, the interviews were analysed for facts about the lives of the young people, such as age, birthplace, educational level, family composition and care, age of being told status, and when or whether they had revealed their diagnosis to anyone. My field notes of each interview were also studied and collated to consider alongside the recorded interview data, following Maynard and Clayman's (1991) argument that field notes must be considered only with more reliable data such as recordings in order to be rigorous. The underlying assumption at this stage of analysis is that participants' talk is reliable and their truth, within context (Silverman 2001).

The next stage of my analysis involved a close reading and re-listening to all the interviews as a single body of text in order to identify recurring themes and patterns in participants' accounts, whilst not losing sight of individual circumstances that might be contributing to the person's perspective. The object was to discover variation, meaning

and examine some of the complex experiences that young people were talking about in order to make connections across the sample. In describing their experiences the assumption was that the young people produce a unique version of their experiences for the interview. For many of these young people the interview was the first time they had told their story, these were untold stories.

Coding

The coding process used was inductive and aimed to recognise an important theme or observation and encoding it. A pre-determined code template was not used. Codes related to relationships were divided into sub codes for example of family, friends, school, sexual, community etc and then were further separated into codes within each group. For example, the code for family was sub divided into brothers, sisters, aunts, uncles, mother and father etc. The dominant theme of disclosure that emerged was sub-divided into intentional or unintended; whether it was to family, sexual partner, friend, work colleague, school, or community. These were then further sub-divided. Responses to disclosure, place and time of disclosure were also coded. The codes were organised and analysis using Nvivo computer software which enabled me to extract information and ideas systematically from the transcripts rather than looking for confirmation of my own ideas.

Part of the analytic process is making connections across codes in order to develop themes and patterns in the data as well as using inductive methods (Crabtree and Miller 1999). Similarities and differences between experiences of participants did emerge at this stage, indicating consensus in certain areas and differences were identified between certain groups. For example, participants in families where HIV was discussed openly expressed more confidence about disclosure to others than those where HIV was not openly discussed.

The codes initially focused around the topic areas of the interviews, and aimed to identify the ways young people spoke about the topics, as well as the themes and critical events.

The 'open coding' process resulted in producing huge numbers of codes and also meant that the meaning of the codes sometimes changed as I went through the transcripts because of how participants talked about the topics. Although I endeavoured to reflect the themes and links used by the participants in the study, ultimately my selection from their narratives and accounts was largely inductive and based on my interpretation of what I felt were the most important themes and events (Letherby 2003). Despite having a clear idea of the possible themes after the interviews were conducted, I found that open coding seemed at times a bit haphazard and reactive rather than planned and systematic. Working with such a large data set resulted in a large number of initial codes which in turn generated many sub codes that at times felt unmanageable. The refining of the codes and sub codes was time consuming but ensured a familiarity with the data. Although the use of Nvivo software was at times challenging it enabled me to go through each transcript line by line and provide a more accurate and efficient storage and retrieval system.

The process of identifying key themes involved not only looking for common elements in interviews but also looking for differences. Looking for 'deviant cases' (Silverman 2001:17); those interviews that highlight something different to the others, allows the researcher to consider the relevance of those that do not conform to the expected pattern. This was explored within the key themes identified from the data. After the difficult process of rationalising and refining the codes, patterns, several overarching or key themes emerged and these formed the data chapters in the thesis. These focused primarily around disclosure and how young people control and manage HIV through the use of different strategies including secrets and lies. Young peoples' accounts also reflect the significance of the particular stigma attached to HIV and how this alters the character of the disruption this brings to identity.

Young peoples' narratives were also examined for evidence of how HIV disrupted biography (Bury 1982) and whether key 'critical moments' (Thomson et al. 2002) could be identified from the data. These two theoretical concepts were used in the analysis of the

data in order to address the research aims – to understand the impact on biography of HIV and the experience of a young person born with the infection. There were many 'critical moments' (Thomson et al. 2002) in young peoples' narratives, but I wanted to focus on the 'critical moments' specifically related to an HIV trajectory.

The overarching themes identified tended to encompass many of the sub themes. For example, disclosure was identified as a main theme, and the sub themes were - disclosure to the young person, subsequent disclosure by the young person to family, sexual partners and friends. Disclosure also represents a major biographical event and one that disrupts a young person's biography and as such is an overarching theme from the data that is explored using the Bury's (1982) theoretical concept of 'biographical disruption' and the idea of 'critical moments' (Thomson et al. 2002).

During the process of analysis I was continually aware of the potential bias as a researcher who is familiar with the issues and the potential for identifying familiar rather than actual themes from the data. As the analysis developed this was less of an issue as the transcripts were coded and themes became more apparent. Throughout the analytical process I had a heightened awareness of the importance of presenting data from the perspective of the young people, to be led by the data and to remain true to the data. Although the data analysis is described and presented as a linear process it was an iterative and reflexive process. This interactivity is described by Tobin and Begley (2004) as the 'overarching principle of goodness' and is seen as a fundamental component of qualitative analysis. There are limitations in the analysis in a doctoral study and the main limitation is that the data is coded and themes identified by one person and only discussed within a supervisory team. Whilst this method may provide consistency, the analysis is likely to have benefited from the input from a variety of people with multiple perspectives with differing expertise.

3.6. Summary

This qualitative study set out to examine the experiences of young people with perinatally acquired HIV. Undertaking research with this group is particularly difficult in terms of access, sensitivity and perceived vulnerability. Research with young people raises issues of power differentials and informed consent that need to be considered and these were addressed within the study design. The process of ethical approval highlighted the need for protection for young people with HIV and the importance of appropriate support to be in place. Qualitative individual interviews were chosen as a method because the topic is both sensitive and personal. This was seen to be the most appropriate approach to hear the stories of these young people. Responsive interviewing (Rubin and Rubin 2005) was selected as a method of interviewing because it is both flexible and adaptable and enables the interviewer to follow up new issues during the interview.

The data was thematically analysed and data driven, allowing themes to emerge directly from the data using inductive coding. Several overarching themes were identified from the data and centred on the issues around disclosure. The data was also examined in relation to two theoretical concepts – first, for evidence of ‘biographical disruption’ (Bury 1982) and how HIV disrupted biography; second, identifying key ‘critical moments’ (Thomson et al. 2002) in the HIV trajectory of young people. These two theoretical concepts were used in the analysis of the data in order to address the research aims – to understand the impact of HIV on biography and the experience of a young person born with the infection. This chapter has outlined the methodology which was designed to address the research questions and explains the decision to use qualitative interviewing as a method. The development of the study has been described in order to make the research process as transparent as possible and support the decisions made in this study.

The following four chapters present the stories of the twenty-eight young people who agreed to participate in this study.

Chapter 4

Finding out or being told you have HIV infection

4.1. Introduction

This chapter explores young peoples' accounts of finding out or being told they are HIV positive. Historically HIV has been predominantly viewed by society as a stigmatising condition because it is associated with sex, drugs, promiscuity and seen as contagious (Ostrom et al 2006; Sontag 1989). As Joffe (1999:40) observes 'in addition to being linked to foreign continents and to out groups, AIDS is associated with various 'perverse' or 'deviant' practices'. Not only is HIV linked to sex, it is linked with risky sex and perceived risk groups, such as homosexuals and intravenous drug users. As this chapter will show the stigma of HIV makes disclosure to children more complex. The voice of the child and young person has rarely been heard in discussions on HIV disclosure as Lesch and colleagues observe:

The voice of the child has remained silent in the disclosure debate. Accessing the perceptions of children and allowing them to provide insight into their lived experiences and articulate their needs and preferences is an area that has remained unexplored and should be addressed as a priority. (Lesch et al. 2007:814)

Therefore, young peoples' accounts of their experiences of being told about HIV are likely to provide some insight into their needs and preferences for being informed of their condition. In considering disclosure, it is important to be clear as to what is meant here by the term. The dictionary defines disclosure as 'the action of disclosing information, especially a secret' (Oxford English Dictionary, 2005). Whilst some participants use the

word disclosure and talk of being 'disclosed to', most talk of 'being told'. Therefore I use the words 'being told' as well as disclosure. Young people talk of disclosure as an event, usually a formal event, but there are some for whom it appears to be a process that happens over time. For many the event of disclosure is focused on the formal telling or naming of the condition by others. However, the process of disclosure is often more complex and subtle, where clues and signals are picked up and interpreted over time by the young person. What is clear from the interviews is that being told is not the only way of knowing.

The first part of this chapter considers aspects of guessing and suspecting that young people engage in when they perceive something is wrong. The second part explores the stories and explanations that young people are given to explain their health problems and experiences. The third part considers the event of being formally told. In the final part of the chapter I consider young peoples' responses and reactions to disclosure and the accompanying advice they recall being given.

4.2. Knowing, guessing or suspecting

The young people in this study have attended hospital on a regular basis for some years to receive treatment and monitor their health. Twenty six (92.8%) participants report regularly attending hospital before the age of ten. Many have experienced ill health and twenty one (75%) recalled being hospitalised at least once. Seven (28%) recall multiple hospital admissions. As well as attending hospital, over 70% of participants report being on medication before the age of ten. Their childhoods have been disrupted by ill health, hospital visits and medication.

Several participants spoke about 'guessing' or 'suspecting' that something was wrong with their health before they were formally told, for example Ruth states:

Ruth: I found out when I must have been eleven or twelve, but I think I knew before that.....I'd kind of guessed already what it was . (aged 20yrs)

Alica and Joshua have been attending the hospital since a young age:

Alica: I knew I was there because, you know I was ill, or you know whatever you want to call it. Yeah I just gathered that I wasn't like normal healthy kids and that there was something wrong with me. And at that point, I don't feel I took much notice, I think at that time it was more my parents that were worried. But at such a young age you don't care because you don't know. But I got used to the routine of coming to the hospital, my dad used to make it a fun day out, we used to sit for ages, I remember getting weighed, coming to see the doctor who would take my blood and stuff. (aged 19yrs)

Joshua: I thought I was going to hospital 'cos I was getting ill a lot, I just guessed I wasn't very healthy, and then as I got older I did begin to think what was I ill with.(aged 22yrs)

These accounts display a normalisation and acceptance of going to hospital but also illustrate a developing awareness that there must be a reason for the frequent hospital visits. The visits to hospital provide the evidence for young people that they are ill and for some the clues as to what is wrong. These accounts also demonstrate how HIV can disrupt children and young people's lives.

Developing this awareness may involve people other than just the young person. Participants are involved in a network of systems other than the family, such as the hospital, school, and other social networks. Whilst the awareness of the name 'HIV' may be limited amongst such networks, there may be a suspicion of something being wrong, but unspoken. Young people know they are different but do not know why; most know they have a health problem but it is not yet named.

Ruth lives with her mother and sister and came to the UK from Africa when she was two. Her father died from HIV. Her mother is HIV positive and as far as she knows her sister is unaware of either her HIV status or her mother's. She says:

Ruth: Because I went to paediatric clinic when I was six and seven and that was the age when I started to learn how to read. So, the thing is there they had loads of posters and leaflets, so when they used to like leave me there, like sometimes I'd play, sometimes I'd sit down and take a leaflet while they were speaking to my mum and I'd start reading. So it was like I'd pick and read and I'd kind of see what it was and I'd kind of guessed already but, it probably didn't really stick in my mind like what it really was, but I knew that's probably what it was.

JD: Why did you think you were going to hospital? Had anyone said anything?

Ruth: No-one had said nothing to me

JD: So how do you think that you found out?

Ruth: Basically through hearing the stuff that doctors said to my mum, cos they probably didn't think I understood one, and two because the leaflets about HIV were all over the place, all over there and three, my mum took medication as well. Yeah, my mum had just started taking medication, so that was another thing, so I kind of put them together and kind of realised

JD: Did you say anything to anyone about knowing?

Ruth: No, I didn't say anything. (aged 20yrs)

Children and young people pick up clues from observing their environment and listening to adults, particularly when they are not sure what is going on. Putting the clues together helps children make sense of what is happening. These clues are gathered from different parts of children's lives, not just the hospital, as Ruth observes her mother taking medication. Clarke and colleagues' study (2005) on children with leukaemia and

Bluebond-Langner's work (1978) work with dying children, also found that children pick up information and cues from their illness experience and environment. They both found that children watched the behaviour of health staff and listened to their conversations. They observe that children use these clues to make sense of their situation because adults do not include them (Bluebond-Langner 1978; Clarke et al. 2005; Chesler et al. 1986).

Ruth is excluded from adult conversation about her health, but she is aware and adopts a position of silent pretence. She displays what Glaser and Strauss call 'suspicion awareness' (1964), where individuals are aware that something is wrong through picking up clues and the behaviour of others. Ruth moves from 'suspicion awareness' to 'pretence awareness' (Glaser and Strauss 1964; Field and Copp 1999). 'Pretence awareness' is described by Glaser and Strauss as a situation where people are aware of what is wrong, but pretend they do not know. Although Glaser and Strauss's study was with terminally ill adults, elements of their concept of context awareness can be seen in Ruth's narrative and may also apply to the experience of young people. However, Ruth's account needs to be placed in context. She has experienced the loss of her father from HIV and was born in a country where death from HIV is common. Her frame of reference already includes HIV which may have resulted in a heightened awareness.

Guessing and suspecting something is wrong has been shown to be common amongst children and young people with a range of chronic illness. Studies with children who have cancer have demonstrated their capacity to understand the nature of their illness long before they have been told (Bluebond-Langner 1978; Chesler et al 1986; Clafin and Barbarin 1991; De Matteo et al. 2002; Instone 2000; Spinetta 1974; Waugh 2003).

Participants' expressed desire to know what is wrong with them varies from person to person in this study. Whereas Ruth had guessed what may be wrong with her, a few participants spoke about wanting to know explicitly. This led some to ask questions. Although some spoke about asking questions repeatedly, they also reported that their inquisitiveness was ignored. This variation is difficult to explain, but is arguably influenced

by character, family context and culture of communication in families. Those participants whose intensity of inquiry is strongest are the ones that tend to keep on asking 'What is wrong with me?' They may well be the more confident or articulate young person, or live within families where there is more talk. It is the experiences of these young people which are considered next.

Those who ask 'What is wrong?'

Charlotte spoke about how she used to ask questions when she was young. She had lost both her parents from HIV before she was five and was raised by her grandmother. Her parents were both artists and despite their deaths remain highly influential in her life, and she spoke of their life force and ambitions. She is an only child and recalls no direct conversations about HIV growing up despite attending hospital regularly. She recalls asking questions when she was seven:

Charlotte: I think, well for several years I'd noticed that it didn't make sense, because if I went to the doctors a lot of the time then obviously I should be ill. Then what was I ill with, and I kept pushing and asking questions and I was always handed off to someone else or given an excuse or told to 'go and play with that toy'.

JD: So what did they tell you? Did they give you any information when you asked questions?

Charlotte: No, nothing I can remember at all.

JD: Do you remember how you felt?

Charlotte: Frustrated because my brilliant crafted plan had failed (laughs). I always had plans to find out, so whenever I had my bloods done I would always take the same person with me so they wouldn't like to be able to say anything without me being there. (aged 19yrs)

Some children experience difficulties in trying to find out what is wrong with them. Charlotte was aware that something was being hidden from her. In trying to find ways of getting the information she wanted she felt thwarted and frustrated. She perceived that she had little control over what she was told and later in the interview spoke about how isolated this left her feeling. The control of information is well maintained within the hospital system, with staff maintaining a silent pretence in order to minimise the cues that could lead to disclosure. At this stage the disclosure process is controlled by adults and children have little power to access information.

Jina: I found out when I was fourteen, I don't think they were planning to tell me, but the doctor sort of persuaded them (parents) to tell me...cos my mum's got it and she's like had to go through loads of hassle and stuff with everything...the doctor was like erm.. 'You've got a disease and it's called HIV' and for some reason I sort of had it in my head that I had that anyway...I don't know why ..cos loads of people talk about it.. (aged 17yrs)

Some participants pick up the reluctance of parent(s) to tell them their diagnosis. Jina links her mum's reluctance with her difficult experience of living with HIV. She displays 'suspicion awareness' in her account both of her mum's infection and her own. Her account also confirms how participants pick up clues from listening to those around. At fourteen Jina had no access or control over when she was told; she had no power in the disclosure process.

Mark's account highlights similar issues of control of information. He is eighteen and lives with his mother who is HIV positive. He does not know his father, and has no contact with his brothers or sisters.

Mark: She (mother) never mentioned the words, but I remember when I used to go to the hospital and say, there was a new doctor who was examining me, she'd write down the name of it and show it to him so that I couldn't see it, or something like that. She didn't want me to know what it

was, she probably thought that I had a big mouth and so didn't want me to find out cos, she probably thought I couldn't say nothing about it, and all of that and she probably thought that I wasn't ready. Now when I was 11, coming up to 12, I was going to one doctor's appointment and I was curious, I wanted to know what this bug was called, what is it like, cos I was innocent, I was young, so I must have gone to the doctors, 'So what is this bug that I have' I said. There was bare hostility inside the room, like silence when my mum just looked at us, she kept looking at us, so I think, I remember they went outside to talk.

JD: Did they leave you in the room?

Mark: Yes, they left me in the room, they went outside to talk and I think the doctor was telling my mum that she should tell me, and my mum would say 'No, he's not ready he is still young, she'd tell him. This is the age I was starting puberty, so everyone comes in, and I was getting worried and thinking what's going on? I didn't know what it was, all I had asked was a simple question and how could a simple question be such a big thing obviously. So the doctor must have looked at me and goes 'Well this bug you've got is called HIV' and I'm like 'Alright', I've heard of it before, and I didn't really think nothing of it innit. I didn't know so for a couple of years, when I learnt a bit more about HIV I knew what it was, but again it didn't bother me for some reasons, I didn't care then, so, I think I was really ignorant to HIV..(aged 18yrs)

This account illustrates the conspiratorial nature of the disclosure process and how breaking into the world of adult secrecy can be difficult for young people. Mark's rationalisation and acceptance of his mother's behaviour and decision not to tell him is based on the belief that children are unable to keep a secret. However, the belief that children will tell secrets indiscriminately is not well founded. As studies into child sexual

abuse have found children will conceal information they have promised not to tell (Pipe and Goodman 1991). Although these young people have not been formally told their diagnosis, or promised not to tell, only one participant spoke of telling a friend when young. No young person recalled telling or sharing their suspicions as a child. Mark's account importantly illustrates how some young people are unaware of their diagnosis before they are formally told. They may be aware that something is wrong, but not all guess or suspect it is HIV nor know what it is. Mark's observation of the anxious and fearful behaviour of his mother demonstrates how difficult disclosure is for parent(s) (Waugh 2003; Lee and Rotherham-Borus 2002). The feelings of fear are transmitted to young people and alert them to something 'big'. Mark's description of the disclosure process shows how being told denotes only one point where HIV disrupts life.

As Bury (1982, 1991) found in his study of adults with rheumatoid arthritis in which he developed his concept of biographical disruption, the disruptive experience of illness is not a one-off diagnosis. He observed that the formal diagnosis brought both fear and relief for people. There was relief at having their suspicions confirmed, but there was also fear about what the future held. Similar feelings are expressed by young people in this study, but the disruption experienced by young people may differ to adults. Bury's concept of biographical disruption was based on an adult-centred model of illness (Williams 2000). HIV disrupts a young person's biography at the point of being told, but further disruption is experienced at different stages of their life and different stages of the disease. Mark's biography is disrupted when he learns his diagnosis, but not greatly. However it is further disrupted some years later when he realises the implications of having HIV for relationships and life expectancy. The disruption HIV brings to a young person's biography appears to be experienced on a continuum and mediated through events.

Charlotte asked what was wrong on several occasions, and she recalls when she was fourteen:

Charlotte: Eventually when I asked again and they asked me 'Would you actually like to know?' and I said 'Yes, very much' and so I got sat down with my grandmother and my uncle and told exactly what was up. I remember being very upset and jogged. I didn't understand the situation at all, I was surprised how I felt really..(aged 19yrs)

This extract illustrates some adults' perceptions of children's inquisitiveness. Charlotte's interest is questioned as to whether it is genuine, and this demonstrates how difficult it can be for children to convince adults. The adults are asking if she wants to know, but Charlotte is unsure what she is agreeing to being told. The young people who asked repeatedly about their condition may well have prompted earlier disclosure from family and doctors. However, Charlotte's question may have been answered at this point because she was older, and at an age where she may be sexually active. Although several participants asked direct questions, some like Charlotte found hearing what was wrong difficult to manage. She found the unexpected feelings that accompany disclosure distressing. Suspecting something is wrong does not insulate or prepare a young person to hear difficult information. Charlotte's life is 'jogged' which relates to things being moved or pushed out of place. The information disrupts Charlotte's biography despite her previous suspicions, which had already caused anxiety. As Bury observes, the disruption in explanatory frameworks used by people demand a fundamental rethinking of their biography (Bury 1982; Williams 2000).

In order to conceal HIV from young people adults use pretence as their main defence. Participants recall various stories and explanations they were given as children and these are considered in the next section.

4.3. Stories and explanations

One of the most common strategies used to explain ill health or hospital visits was to cite other non-stigmatising health conditions. Other explanations provided included existing health problems that were linked to HIV. Many of the young people

in the study had complex health problems, and experienced side effects of medication. The symptoms of HIV and side effects of medication reported included: tiredness, sickness, diarrhoea, poor growth, respiratory infections and other recurring infections. Many of these were explained away by selecting a less stigmatising or serious condition.

‘I thought I had asthma’ – the use of non-stigmatising health conditions

Participants recall that, prior to being told their diagnosis, they attributed hospital attendance and the symptoms of HIV to a range of conditions. For example Denisha remembers:

Denisha: I just thought I was just severely ill, at first, my mum said like I was a late developer anyway, so with speaking and walking and all that stuff, so I just thought it was ‘cos of that, just coming to get checked up.. she never said anything else. (aged 18yrs)

These explanations provided ‘cover’ for taking medicines, blood tests, prolonged and regular treatment, and for some participants, hospital admissions. Some of the explanations and what Funck-Bretano (1997) refers to as ‘illness deception’ are evident in other studies. Instone (2000) and others for example, identified similar patterns of behaviour and illness deception in her study of HIV infected children and parents where parents linked medical treatment with non stigmatised, but related conditions (Vaugh 2003; Wiener et al 2006 2007b).

Illness deception results in creating a protective biography. Telling a child they are having treatment for a non-stigmatising condition protects them from the stigma of HIV. Goffman (1963:46) observes that families create a ‘protective capsule for its young’ within which a stigmatised child can be ‘sustained by means of information control’ to avoid them knowing. However, creating a protective biography may have the unintended

consequence of affecting the trust that young people have in adults, and promote feelings of betrayal once they discover that they have been deceived.

Jina was born in Zambia and came to the UK when she was three after her Dad had died from HIV. She is the only one of six siblings/half siblings infected with HIV in her family.

Jina: I thought I was coming to the hospital because of my asthma... I thought they weren't telling me the truth. I just couldn't be bothered to ask, they never tell me anything anyway.. (laughs) I used to have asthma when I was little and I used inhalers and stuff and I thought the medicines were for that.

JD: Did you believe that then?

Jina: Yes (laughs), I feel so stupid now (laughs) (aged 17yrs)

Young people can feel foolish and embarrassed once they are told their diagnosis and realise they were taken in by the false explanation. They can feel stupid for believing the story given to them, however convincing it was. As Abadia-Barreo and La Russo observe in their study of Brazilian young people:

Lack of communication about HIV/AIDS creates a context of confusion and mistrust, is detrimental to psychosocial development and coping, compromises disease, knowledge and increases vulnerability to risk behaviour. (2006:38)

Louisa, like Jina also thought she was attending hospital for a linked health condition. Her father died from HIV when she was four. Her mother and step father are both HIV positive, yet she is the only one of seven siblings infected.

Louisa: I'd obviously been in and out of hospital but I always thought that the reason I was so ill was because of the pneumonia which I was always told because obviously they didn't want me to know.....I think I was told that my

lungs were weak, which they were 'cos I was born prematurely and my lungs collapsed. I wasn't even expected to be living right now, which is so weird.... I really thought it was just pneumonia, like even afterwards, even after I found out, and the school would say, 'What are you going to the hospital for?' I'd say 'Oh pneumonia'. That's just what was more than likely, you know, programmed for me, 'You've got pneumonia'. (aged 17yrs)

Louisa found her parent's explanation a credible story. Her account also highlights the severity of HIV and the compromised health of many of these young people. Some young people were not expected to survive and their cover story may not have been developed with a long term view. Although Louisa knows her diagnosis she finds using pneumonia as both an acceptable and now comfortably familiar cover story. The story has proved effective in the past and carries some legitimacy as it contains an element of truth. Pneumonia has become an established part of her illness narrative. Her past protected biography is now part of her present. Louisa's use of the word 'programmed' reflects the control others have over information about her condition and also her lack of agency and power in the situation. She has no ownership over her health and her detachment reflects her powerlessness.

Whereas some participants were given a simple reason to explain hospital visits, others such as Jonas were given more confusing stories:

Jonas: I actually didn't believe the exercise story, that they told me, I don't know, well my Mum told me that they took me back to Africa and then I got unwell and came back to England and I was in hospital for months and I almost died at that point and they had to insert a gastroscopy button because I wasn't eating anything. So I always believed that there wasn't anything, No, I believe that I just caught some disease in Africa and it affected my legs.

When I think from 12 to 15 I had three operations in the space of that time. So that was very hard at times so I don't think I would have wanted to know about it back

then. But then one day out of the unexpected I'm happy with life, I could walk, I could fit in more and then I'm told I have HIV which really upset me you know.
(aged 15yrs)

Cover stories can be complex. Jonas believed he was responsible for his lack of progress, because he did not do his exercises, despite his suspicions. His sense of guilt and blame, however unintended, were a consequence of the cover story. Participants are not able to check their stories with anyone, as they have no access to accurate information. Jonas's reflections illustrate the burden an HIV diagnosis can be for some young people when their lives are already disrupted by other issues. Despite his disability, he had just found a way to 'fit in' and manage the stigma of limited mobility. Being told his HIV diagnosis brought further disruption to his life and his difference re-emerged. The stigma of disability has been replaced by the stigma of HIV. Bury (1982) and Charmaz (2002) observe how adults re-arrange their thoughts and relations with others in light of the new information and adjust to a new situation. Jonas's experience means he has to rethink his biography and sense of identity (Pierret 2000; Charmaz 1987, 2002). His explanatory framework has been disrupted (Williams 2000).

One of the unintended consequences of children not being given accurate information is that they try and make sense of their own story of what is wrong (Bluebond-Langner 1978; Chesler et al. 1986). It is not clear why some participants believed the stories and explanations given and some did not. This may well have something to do with the legitimacy of the story, how convincing, or how much sense it made to the young person. It is also relates to the culture and patterns of relationships and communication within families. Family responses to children with chronic illness are mediated by culture as it influences communication. How comfortable families are with open communication regarding HIV is influenced by the patterns of communication already established with children (Chesler et al 1986; Lee and Rotherham-Borus 2002; Miah 2004; Wiener et al. 1996).

Whilst some explanations recalled by young people were less convincing than others, cover stories used to explain frequent hospital visits were generally more accepted and for some, seen as 'normal'.

4.4. Going to hospital is part of life

Most participants identified hospital attendance as a central feature of their childhood experience. Several participants reviewed their past and perceived attending hospital as 'normal' or 'second nature'.

Neema: Cos I had been going to the doctors every three or four months, but I didn't really know it was anything different 'cos I just had it all my life, so I thought everyone did it...(aged 17yrs)

Ruth: At first I thought all kids went, I thought that everyone went to the hospital in general. I thought it was the normal thing to do (laughs) and then, like after a while I started thinking, I was possibly ten, I definitely knew I was coming in because I was HIV, no one had said anything to me. (aged 20yrs)

Catriona: Ever since I was little and growing up, I've grown up with it, going to hospital appointments, having my blood taken, stuff like that, It's always been in my nature so it's like second nature to me now it isn't odd, cos I've always done it. (aged 17yrs)

The familiarity of the process of hospital visits has become part of each young person's biography. The demands and routines of HIV have become part of their life and behaviour. Some participants understood that there was a reason why they were going to hospital and suspected they were unwell.

Matthew: I kind of knew something was wrong with me 'cos I always went to hospital, but I didn't quite know why. ... I thought it was what everybody else did, but when I asked my friends they said 'that's a bit odd'...(aged 18yrs)

Participants like Matthew discover they are different only when they are able to compare themselves with others, usually at school. In comparing his life with others Matthew becomes aware his 'normal' is different to others. Despite young people suspecting the explanations and stories parent(s) gave, they report generally accepting them. They also report that they comply, as they perceive that they have very little control or power over the flow of information. They are unable to access the information in their own right at this point and have no allies to help. Sefu recalls asking his mother why he was going to hospital, he was ten:

Sefu: I always thought it was for something else, I never realised properly probably didn't really want to know in a way. There was one time I asked her about going to hospital, but she didn't really say much, she just said, 'Just cos you have to' so I left it at that.. it was never mentioned again... I took medicines from being little and was told just that I just had to take them for no reason, it was like just that I had to take them cos that's what I was meant to do. (aged 15yrs)

Sefu's acceptance of instruction is coupled with the understanding that his mum is not questioned. Whilst some participants attended hospital without asking many questions, others did ask questions and the following section looks at those young people whose questions were answered.

4.5. Having suspicions confirmed

Although some participants spoke of suspecting something was wrong before being told (as discussed in section one of this chapter), there is a difference between suspicion and confirmation.

Ruth: When I was told properly, my mum was there and they asked me whether I knew why I came to the hospital, and it was quite funny cos I just remember laughing and I couldn't stop laughing, and I don't know why I was laughing, but I knew the answer but I didn't really like want to say and like when you put me in a position at that age, you tell me, I listen. But if you put me in a position where I had to talk I would probably just laugh, I knew the answer but I didn't really, I think maybe it was I didn't want to say it.

JD: Why do you think that was?

Ruth: Because maybe it was realising that maybe it's actually true actually hearing it now out loud for the first time, it's actually true, so that was probably one of the reasons. (aged 20yrs)

Being confronted and exposed engendered feelings of awkwardness and embarrassment in Ruth. Her account highlights the power differential between a young person and adult in the disclosure process. The deferential relationship between Ruth and her mother and doctor is evident, and inhibits Ruth's response. However, all the time HIV remains unspoken there is a chance that it may not be true. Hearing the words out loud confirm the reality. As Jina reflects:

Jina: For some reason I had it in my head that I had it anyway, I was just expecting the worst, it was either that or cancer or something. Well, I didn't think I had cancer otherwise I'd be losing my hair so, I knew it was something bad...but I still was so shocked to hear the words. (aged 17yrs)

Whilst young people do not know for sure they have HIV until they are formally told, there is always the hope that their illness is maybe something other than HIV. Despite suspicions participants still find the reality of being told they have HIV shocking. The shock may be a response to the stigma of HIV, because being told is the beginning of the realisation of stigma. Suspecting they had cancer was a common response amongst

participants. This may be because it is a familiar, but serious illness and one that people may be reluctant to talk about. Jina believed that whatever was wrong was 'something bad', because it was never named, and never spoken about. It is what Clafin and Barbarin (1991) call a 'dangerous secret' and therefore it must be 'bad'. As Jonas reflects:

Jonas: I had no idea at all what I had, I just knew it was bad. (aged 16yrs)

Whatever clues or signals Jonas picked up before being told from the silence, he knew it was not good. As well as being shocked by the news of HIV some participants spoke about other reactions:

Samuel: I really thought it was going to be something awful, when they told me HIV, it was funny I was kind of relieved, I thought it was going to be worse, mind you what is worse than HIV?(laughs).....I thought they were going to tell me I was going to die. (aged 18yrs)

Samuel's relief reflects his fear of dying. His extract demonstrates how not knowing did not protect him from distress or anxiety, as other studies have shown (Wiener et al. 2003; 2006; 2007b). Relief as a response to diagnosis has also been identified in studies with young people with chronic illness including HIV (Waugh 2003; Chesler et al. 1986). Not knowing does not prevent children and young people guessing what is wrong. Studies have found that children interpret the silence of adults as an indication that something is wrong and as overt or covert clues to the child not to talk (Van Dongen-Melman and Sanders-Woudstra 1986; Bluebond-Langner 1978). Karon and Vernick (1968) refer to this as a 'conspiracy of silence'. Instone's (2000) study found 'children have a long wait in silence before they are told'. Other studies of children and young people with chronic illness, (Chesler et al. 1986; De Matteo et al. 2002; Instone 2000; Lester et al. 2003; Van Dongen-Melman and Sanders-Woudstra 1986; Waugh 2003) have also found that where children do not receive information or a 'convincing reason' they fear the worst. The experiences of being told about HIV infection vary widely and these experiences are considered in the next section.

4.6. Naming the difference- the event of being told

Participants' experiences of being told range from those who had suspected they had HIV from quite a young age, to those who had no idea until told in the doctor's office. Some participants were told unintentionally rather than in a planned manner. Each participant has their own unique story, and whilst a few were told gradually over a period of years, most were told outright.

Age

The age at which young people reported being told their diagnosis differs, and the mean age of disclosure was 12 years (n=28). The youngest age of full disclosure was 5 years old and the oldest was 16 years. Twenty three young people (82%) were told their full diagnosis when they were over ten years old and of these, four had been given partial information before the age of ten. Nearly a third of participants 9 (32%) were over the age of fourteen when they were told their diagnosis, and of these 7 were female (78 %). Even when these figures are adjusted for the difference in representation of men and women in the sample size, more young women (39%) than young men (20%) were told their diagnosis over the age of fourteen. From this small sample it is not clear why young women report being told at an older age. It may be because young women are perceived to be less sexually active than young men, or that parent(s) are more reluctant to tell young women and may be more protective towards them. Parent(s) may also perceive young men to be more sexually active, less responsible and are less protective towards them. These differences may also reflect society's perceptions of the differences between female and male sexuality. The young people in this study came from ethnically diverse backgrounds with over 60% born outside the UK and over 50% from African countries; therefore there may be cultural differences in concepts of what can or cannot be said to young men and young women.

Place

When recalling how they were told or found out their diagnosis, participants all included details of the setting. Many recalled precisely when they were told, where and who did the telling. Nineteen (68%) young people reported being told their diagnosis at hospital, by health professionals with a parent present. Four (14%) young people were told at home by their parents, three by their mothers, one by both parents. Two young people (7%) were told by social services. Hospital was the most common setting for being told and participants talk focuses on the hospital as a central part of their experience. The hospital is the place where young people are taken as children where their unspoken, un-named health condition is treated.

Although HIV may be talked about amongst adults at the hospital, it may not have been spoken about or named with young people until the formal event of being told. The hospital then becomes identified as the 'safe' place where HIV may be talked about after disclosure.

Neema and Joanna were told at home:

Neema: I was eleven, year six, it was the day after I had finished primary school or something like that and it was really just on the sofa, me, my mum and that's when she just told me. We were watching TV about drugs and stuff on TV..(aged 17yrs)

Joanna: I was about thirteen.....I think it was in my house in the kitchen, yeah it was, they told me, they didn't tell my brother and sister but they like told them to go and watch telly or something, and then they just told me...I think they just told me but really nicely and everything. (aged 18yrs)

These extracts illustrate how other significant events happening act as markers to the memory of being told about HIV. Both accounts are characterised by the normalcy of the

event and the straightforwardness of how they recall disclosure. Joanna's extract reflects her appreciation of the way she was told and the importance of how she was told. Ben also recalls:

Ben: I first found out when I was five, but when you are little you are a big mouth aren't you so my Mum decided to tell me at first that I've got a blood disorder, which is the truth. When I was five, she told me I was ill and I had to take this medicine to keep me alive, which is technically the truth as is it a blood disorder, and I believed her for a bit so when I turned six, I asked my mum what is the truth and she was always quite open and I had this big trust in her which was good. And she said to me 'We have to go to the hospital as I can't tell you exactly the truth as it hurts me too much to explain to you', so we went to the doctors and I watched this film and we all had a serious talk about condoms and stuff, and then we watched Titanic, as at the time it was my favourite movie. (aged 17yrs)

Young people look for the 'truth' in the disclosure process because they have lived with the experience of half truths and suspicions. Ben's narrative highlights his acceptance that his mother has difficulty in telling him the truth. This extract demonstrates the loyalty and protection young people feel towards their parent(s) and how this serves to maintain their position of pretence. The disclosure process involves difficult truths and the distress experienced by parent(s) and young people is evident in Ben's account. Mothers with HIV have to face the emotional issues of guilt and blame and these have been identified in studies as key factors in their reluctance to tell a child their HIV diagnosis (Lee and Rotherham-Borus 2002; Waugh 2003; Wiener et al. 2007b). How parents tell young people is influenced by their relationship and their story of how they became infected. Ben's father had died from HIV and according to him both parents had a history of drug use. Ben was one of the few participants who spoke about being able to talk to his mother about HIV, and he identified this openness as significant in helping him cope.

Most participants reported remembering the event of disclosure precisely, and we now turn to the actual event of being told.

4.7. The formality of being told

Most participants recall being told as an event when HIV is actually named, but they also talk about it as a process. For some it is both. This process includes picking up clues, and making sense of hospital visits, investigations and treatment. Some participants describe being given small amounts of information when young and a fuller explanation once they are older.

Partial and Full Disclosure

Funck-Bretano (1997) who conducted some of the earliest work into HIV disclosure identified partial disclosure as the most common pattern of disclosure to HIV infected children. Four participants in this study distinguished between full and partial disclosure, although they did not use such terms, more often speaking about being told a 'bit' or a 'little'.

Becka: I knew what it was to do with, I probably didn't know the name but it was the good guys and the bad guys early on, when I was very young, that's what was being checked on you, which ones were in you, and that was why I had to go to keep going to the hospital.(aged 17yrs)

Ben: My Mum talked to me about good and bad cells when I was young like about 4yrs, I didn't really know what she was on about but I guess it explained a bit to me.. but I was confused by it all. (aged 17yrs)

As Ben observes, for some young people being told about their diagnosis in vague terms added to their confusion. Some participants spoke about developing a general awareness as they were growing up.

Becka: When I was little they didn't sort of say 'You have HIV' they sort of explained with..there were little books and stuff and sort of explanations they're quite funny looking back at them (laughs). Yeah, the good guys and the bad guys, but because you are so young you don't question it, I mean the doctors tell you to take your medicine and you do. I don't remember a time when I didn't know I had it, I just remember being aware all the time, so I guess I must have been told when I was quite young....(aged 17yrs)

Participants recall euphemisms similar to those in other studies with children with chronic illnesses such as cancer and leukaemia (Clarke et al. 2000; Chesler et al. 1986). The use of euphemisms in this study may be partly explained by the fear of the stigma of HIV and the risks of unintended disclosure by children. Euphemisms and silence have been reported in other studies with children and HIV to avoid openness about illness (Wiener et al. 1996). Despite the use of euphemisms Becka recalls being aware of what was wrong. The following section looks at where participants were told or found out their diagnosis and who told them they were HIV positive.

Being Told

Participants describe being told as an event, it is the formal telling. For some it may be the naming of the unspoken health problem, for others it may be the first time they have heard that they have HIV infection. Regardless of how participants are told, the event acts as a marker of a new part of their biography that now includes HIV.

Sarah was nine when she was told:

Sarah: I do have a clear memory of like how it was and I think that will always stay with you..., I just remember crying 'cos you know when you are young, you know a little bit about it, and you think you are going to die...(aged 23yrs)

Sarah's linking of HIV and dying reflects Bury's (1982) observation that one of the consequences of chronic illness for adults is profound disruption because it involves the recognition of the real possibility of death. Charmaz refers to this as an 'awakening to death' (1997:40). This recognition and awakening is evident in young people's narratives, but is heightened with HIV because of the nature of the public discourse. Her linkage of HIV and death also reflects the social discourse that has been constructed around AIDS/HIV, death and fear (Sontag 1989; Mellins et al. 2002; Wiener 1996).

Jonas who was told at an older age, fifteen, recalls different concerns:

Jonas: I found out earlier this year I had HIV and Dr S told me when he first told me I was very upset. I was a bit scared and I didn't know how to take it....I had heard about HIV and I thought it was a sexually transmitted disease so I was wondering how (Silence) ... I thought it could only be passed on sexually, so I was wondering...cos I hadn't had sex, then the doctor explained to me that it can be passed from mother to child. So that's when I learned that my Dad, parents also had it, and I was really shocked, I just didn't know how to take it.
(aged 16yrs)

Jonas's extract highlights one of the particular issues for this group; that is the route of their infection. He has sufficient knowledge about HIV to know it is sexually transmitted and his confusion is resolved when he realises that both his parents are also infected, and his mother passed the infection to him. The disclosure event exposes several secrets at the same time and this presents young people with a complex web to untangle. This new information disrupted Jonas's biography on several levels; his past biography is reviewed and reconstructed and his stories and experiences are re-framed. His past is based on beliefs about his parents' lives and behaviour and these are now questioned. His taken-for-granted assumptions about his family are disrupted, and this necessitates a fundamental rethinking about his life and story.

Young men and young women presented their disclosure experiences in different ways. The young men tended to describe the event in less detail than the young women, and mentioned it when talking about other issues. The young women remembered more detail and talked about feelings associated with disclosure. Young men's talk about disclosure was woven throughout their accounts rather than contained in an answer to a specific question. The following extracts are included to illustrate some of the differences.

Sefu was the youngest participant in the study and was quietly spoken and measured in his responses. He was told his diagnosis twelve months previously:

Sefu: I was thirteen, I sat in that chair, (points to my chair) the doctor sat there (points to another chair) and the doctor just told me with my mum there as well, and that was really it.

JD: And what did you think?

Sefu: I was very sad and a bit scared as well.

(aged 15yrs)

Sefu's fear and sadness were powerfully communicated in the interview through his quietness and body language rather than his words. He sat with his head down as he recalled how he was told his diagnosis. Unknowingly I had interviewed Sefu in the same room he had received his diagnosis the previous year, and he recalled where he and the doctor sat when he had been told; this may well have had an impact on his reactions to my questions. Sefu spoke about having no idea he had HIV, and less idea that both his parents were also infected. As far as Sefu is aware, his younger brother is unaware of either his or his parents' HIV status. Although he recalled his experience in very matter of fact language with few words, his disclosure experience had a profound effect on him. Louisa was an animated and engaging young woman who appeared to recall her disclosure experience with ease:

Louisa: I was fourteen, the doctor and mum told me to come and sit downand they basically told me and to be honest as soon as they said "You're HIV positive" I thought I'd better start praying, Oh my god you might die and that's basically what ran through my head, I was just like, 'HIV and I might die', and as soon as I thought that I thought 'Oh my gosh, my Dad' and I thought 'Right that links it all together' (Father had died from HIV) and then they told me how I got it, I basically caught it at birth and it was absolutely crazy at the time. (aged 17yrs)

Three years later Louisa is still able to describe and recount her emotions and feelings. Her account communicates her fear and panic at learning she had HIV infection. Like other participants Louisa links HIV with death and realises that her parents were also infected. Whilst there may be differences in how young men and women describe their experience of disclosure, the memory of the occasion remains.

A consequence of being told may be that past events make more sense to participants'.

As Joshua recalls:

Joshua: I think I was about twelve, thirteen, I found out from my doctor, I think so, my mum brought me into the hospital and the doctor explained I had something. It did come as a bit of a shock to me, maybe it's just me, but I didn't kind of hit the ceiling, I didn't know what to make of it. I just kind of let it slowly mould into me as part of my life.

JD: Can you remember how you felt?

Joshua: A bit of confusion and maybe a little bit of denial that comes to you there first as well, but I guess it's ...basically it's kind of in your face and you can't really stay in denial too long, it kind of explained a lot anyway to be honest.

JD: In what way?

Joshua: For example going to hospital

(aged 22yrs)

Being told helped Joshua understand why he had been going to hospital, and make more sense of past events and the unexplained in his life. His responses to his diagnosis reveal an acceptance of HIV as now part of his life and his identity. Likewise for Lakeesha, disclosure helped explain why she was ill:

Lakeesha: I was so ill all the time, and then like when I was nine, I then got tested again and I was positive. My whole family got to come in and then we were all got tested and I was positive and they were negative. They were all negative and then my mum was positive as well. And that's when, Oh this is quite a bad bit, then I remember we went into the doctors room and he said that I'm HIV positive and I'm gonna die. Being told you have HIV is awful, just hearing those words makes you feel as if you are going to die, it was so scary....(aged 17yrs)

The impact of being the only sibling infected in a family is distressing. Being told formally sets Lakeesha apart from others in her family, but it does explain her illness. Because HIV connects her to her mother, relationships in the family are likely to be altered. She, like others, immediately links HIV with a fear of death. Lakeesha's mother discovered her status at the same time, whereas most mothers know their HIV status before that of their child's.

Being told is an important marker in the lives of young people and for those who find out in a particularly unexpected manner there is additional distress. The experience of these participants is considered next.

The unexpected event – accidental disclosure

Three participants experienced unintended disclosure. Jahia overheard a conversation between her mother and sister, Amy overheard her mother's telephone conversation, and Matthew was told when he visited the orthodontist.

Matthew recalls his experience:

Matthew: Well, I was at the orthodontist and I remember the orthodontist telling my Dad, commenting 'And Matthew's HIV positive' and I remember my Dad looking at me with one of those stares that I'll never forget, you know, I don't think...his face was pale, he didn't really know what to say. I didn't really react, I don't know why.. (aged 18yrs)

This account highlights how the shock of being told can immobilise reactions. Matthew's focus on his father's response reflects the importance of a parent's response and how most participants look to and take their lead from parents. Later he reflects on how he found out:

Matthew: It wasn't the best way to find out, but somehow you get through it, talking about it would have helped I think, but no one seems to do that well in our family, Dad is hopeless unless it's about school or money...(aged 18yrs)

Families have different patterns and cultures of communication. Matthew's family do not talk much, and they communicate in different ways. He accepts that his Dad was not able to talk about what happened, even though it may have been helpful for him. Some families communicate verbally more than others and an HIV diagnosis does not necessarily result in greater or lesser communication, but may just highlight the existing pattern within the family.

Amy is now eighteen and has a two year old son. When she was sixteen she found out she had HIV infection by overhearing her mother on the telephone. She describes this relationship as turbulent relationship which resulted in her being cared for by her

grandparents. According to Amy, her mother has a history of drug use and Amy suspects she has worked as a prostitute in the past.

Amy: My mum was talking in bedroom to the hospital and she was going on the phone going 'I can't tell her, I can't tell her' and she got off the phone and I said 'What is it you can't tell me?' and then it all came out from there.

JD: What happened?

Amy: She said 'You've got something that you wouldn't have known you had' which I didn't know, just all I knew is that I had a blood disorder, she said 'and I've had to hide it from you to protect you from telling anyone' and blah blah blah, and I am going mad. I was literally shouting my head off cos she didn't tell me and then I rung the hospital and said 'Is it true? I've got HIV?' and they said 'Yeah, but how did you find out?' and I went 'Well I overheard my mum talking to you'. So they made an appointment for me to come down and speak to them and they really explained it from there.

I was pretty mad but first thing I went down and what I done is told one of my friends and my friend, well it was a close friend, but she didn't believe me and went round telling everybody that I was lying about having HIV. Then they actually believed it, so I walked out of school then 'cos everyone knew.

(aged 18yrs)

The trauma of finding out her HIV status profoundly affected and disrupted the course of Amy's life. Although she acknowledges that her mother concealed her status, to both protect and prevent her from telling anyone, she remains angry. Amy's first instinct to tell a friend highlights the risks in telling others, because it has uncontrollable consequences. The issues about telling others will be explored in chapter four. Amy removed herself from the situation to avoid the consequences of disclosure because she feared the stigma of HIV. She later discovered that staff at her school had known her status for many years,

but were not permitted to tell her. When she recalled this in the interview, she spoke about feeling like the 'last person in world to know'. She felt she could not cope with being at school if everyone knew, so she left school and did not sit her GCSEs. The disruption of HIV meant Amy had to re-organise her life and her relationships. She had to find the resources to cope with the disruption.

As Bury (1982) observes, the disruption that chronic illness brings to biography impacts on everyday life and relationships, and individuals have to find the resources to cope. This is likely to be harder for young people than it is for adults as they may not have the same established sources of support, Amy's resources are limited and her family support fragile. The stigma of HIV exacerbates her disruption because Amy fears the reaction of others and this influences her behaviour.

Where disclosure is unintended the consequences cannot be controlled by parents or medical staff. The control of information was passed either to someone in the network of people who know, in Matthew's case the orthodontist, who unwittingly assumed Matthew knew his status. In Amy's case her mother was unaware her conversation about HIV was overheard. A consequence of unintended disclosure is that there maybe little support in place for the young person following disclosure.

The disclosure experience is an event that becomes a reference point for young people. HIV is now formally part of their life and identity. How young people respond to disclosure marks the beginning of a new biography that now includes HIV, and this is considered in the final section.

4.8. Immediate reactions and responses

Participants described a range of initial and long term responses to 'being told' their diagnosis. As already highlighted these include shock, disbelief, denial, panic, fear, anger, and sadness. Questions such as 'Why me?' are common and hard to answer. As Blasini

and colleagues observe (2004), reactions to an HIV diagnosis reflect 'normal' grieving reactions with stages similar to those experiencing loss as described by Kubler-Ross in her work with dying people (1969,1983,1987). She identified denial, anger, bargaining, depression and acceptance as five stages experienced by people facing death. These stages are not necessarily chronological, experienced singly, nor time bound and may take place over many years. Louisa reflects:

Louisa: I just felt shock and I went quite reserved for a couple of days, I didn't really want to talk to anyone, I felt, what's the word, I felt a little boxed out for a bit, I don't know why, felt quite, I suppose like a bit of an outcast. Cos I knew that none of my other sisters and brothers had it. I thought why only me? (aged 17yrs)

Louisa was fourteen when she was told her HIV status. Disclosure made her feel stigmatised and different from other family members. Louisa now perceives herself as an 'outcast', and stigmatised, set apart from her brothers and sisters. Even though she may have already felt different; this news formally confirms her difference. The range of reactions in young peoples' accounts are similar to those reported with young people with other life limiting conditions, such as cancer (Wiener et al. 2006, 2007b) and one prominent response to disclosure of HIV in this study, is the fear of dying. Sarah recalls her response:

Sarah: I was just crying to my parents, I'm going to die, my understanding at nine years old was that you are going to die soon to be honest and I just thought I'm going to die soon, I just thought it was like AIDS. (aged 23yrs)

Sarah associates HIV with AIDS, and AIDS with death, mirroring the social discourse that has particularly developed around AIDS. In addition to the fear of death, and being upset, anger was also a common response of participants:

Ben: I got angry and upset and then started getting mood swings, I kept on getting ill so I kept on getting angry. (aged 17yrs)

HIV has therefore disrupted and constrains Ben's life. As Bury (1982) observes the disruption from illness entails constraints on self, as illness can limit and restrict. Ben links his anger with his illness, whilst Jina's affects her behaviour:

Jina: Apparently I went through a really rebellious stage afterwards so perhaps it did have an effect, I bunked school, I just didn't bother going to school. But it's just like, I don't know, anger that was slowly coming out ruining my life instead of everybody else's. (aged 17yrs)

Jina's anger has affected her life chances and disrupted her life. HIV has disrupted her relationships and social networks. Leaving school has resulted in her life and relationships having to be re-organised (Bury 1982; Charmaz 1997). However, disclosure cannot be divorced from the personal and social context of a young person's life, because these influence responses and reactions. Jina may have already been experiencing difficulties at school before she was told her HIV diagnosis. The disruption young people identify that HIV brings cannot be seen simply as cause and effect because many participants have had a disrupted life since they were very young. Whatever participants' immediate responses on being told, what is clear is that being told you have HIV disrupts life in complex and subtle ways. As Joanna reflects:

Joanna: Oh, before apparently I was like really happy and like didn't care about anyone (laughs) and everyone said I was really cheerful... But once I found out everything kind of stopped. I just like, I didn't really play after that and me and my brother, who's my age, were really close before then and we'd play sort of fighting games and stuff 'cos I was kind of a tomboy and that just stopped. I think it affected our friendship quite a bit 'cos kind of, you know we went our separate ways after that. (aged 18yrs)

Being told you are HIV positive results in a different view of self. HIV changed how Joanna saw herself and as a consequence her relationships within her family changed. She believed her brother was unaware of her status, but felt that HIV had separated her from him. Her life and close relationships have been altered and she experienced feelings of depression after being told. When her siblings were sent away for schooling she remained at home, and believes this was because she had HIV. A diagnosis of HIV also affects other family members. Lakeesha recalls her Dad's response immediately after she had been told her diagnosis:

Lakeesha: My Dad said he's lying, (the doctor) he goes 'Don't believe him, he's lying' cos I remember we walked out of the hospital, he grabbed me on my shoulder and he was like, 'Don't believe what they're saying, they're lying to you'. I remember inside the doctor's room, but as for what happened after I don't remember, I think we got a KFC after, really awkward. (aged 17yrs)

Other family members also experience shock. Lakeesha's mother and sister were also infected and her father was the only one found not to be infected. HIV can both exclude and include family members. For those infected there is the shared experience which may create a bond, but this may also create separation of those infected which in turn alters family dynamics. There are unintended consequences that affect family relationships as Joanna explains:

Joanna: After I was told, I kind of closed into myself. Like ever since I found out I would keep that a secret from everyone, even my parents, I started keeping other stuff secret so I wouldn't tell them what was going on or what I felt and stuff like that. So I cut off from everyone, including them. I just found that if I close off all emotions then it would never come out. That's when I started to go into a depression really, it was just I didn't talk to anyone, I didn't trust anyone, I sort of don't trust my parents now with most things, which is

obviously quite hurtful to them, I don't share anything with them now...(aged 18yrs)

Keeping HIV secret in order to protect young people from distress and prevent disclosure can raise issues of trust for young people. Responses such as Joanna's can lead to greater isolation for young people. Ruth also describes the lack of support after disclosure:

Ruth: It sort of felt I was just left with it, Mum was relieved, but she had known for ever, I had just found out and I think they forgot about that, it was really difficult.. I didn't really have any reassurance; it felt really uncertain and unsafe. (aged 20yrs)

The impact of disclosure on young people can be underestimated by those doing the telling, because they have usually had longer to adjust to the diagnosis. The need for support and reassurance can be forgotten because the telling is so difficult.

Charlotte: There was no conversation once we got back home it was very much 'Let's get back to normal attitude, thanks goodness that's over.... There was no re-assurance or support, it just kind of got put away and forgotten...I think my feelings somehow like got forgotten once it was over..(aged 19yrs)

Some participants perceived that the focus was on getting the telling over for the adults. The emotional needs of the young person got lost in the process of disclosure. However, what did not get lost were the key messages that accompany disclosure.

'I was told it was best not to tell'

Participants describe how disclosure reinforced the stigma of HIV. Young people were told by parents and health professionals not to tell others because of the possible consequences and this advice contributed to the overall framing of disclosure. Michaud and colleagues (2009) Swiss study found that biological parents, especially HIV positive

mothers insisted on young people not disclosing their status to others for fear of stigma. Disclosure brings the reality of the stigma of HIV to young people.

As Jahia and Sefu recall:

Jahia: Being told didn't really change that much, because like I said it was like I always knew but I just didn't know the name and it was a name for something that I just never knew what it was. So it was just like a name to me really, but it made me feel sad, cos I knew it wasn't good to have.(aged 15yrs)

Sefu: I now knew I had an illness..it was a big secret kind of thing and I kind of knew not to tell...that sort of went without saying..because just like nobody need tell someone like you have HIV, ..do you. I didn't know much about it, but I knew it was not a good thing to have. (aged 15yrs)

Both Jahia and Sefu were aware that HIV was not a good thing to have, but it is not clear whether they knew that HIV is stigmatised. The social discourse of HIV that has developed is focused on the negative and fearful aspects of the virus. Most participants recalled being cautioned to possible stigma and discrimination:

Ben: Mum did say, it was best not to tell anyone or say anything because people will start judging you before they know the facts, just like not come near me and stuff. (aged 17yrs)

Jonas: My doctors told me not to tell anyone 'cos he said that children in England are quite nasty with people that have HIV.....can be nasty. (aged 16yrs)

These accounts illustrate how young people perceive HIV as represented in society, and how they are warned about potential discrimination. HIV is characterised in negative and

discrediting terms and this extends to those that carry and can transmit the virus (Joffe 1999; Sontag 1989).

As Neema reflects:

Neema: Like if you had it you might be a slut or something or you might be gay or whatever, like it's associated with bad things, like if you've got it then you're a bad person. I found that. (aged 17yrs)

Young people link the negative associations of HIV with themselves. If HIV is bad, then they must be bad. Scambler and Hopkin's (1986) concept of 'felt and enacted stigma' in relation to epilepsy identifies the fear of stigma as 'felt stigma'. Felt stigma is linked to the shame associated with certain conditions, such as HIV. It is the shame and fear of the stigma of HIV leads to the concealment of the condition (Scambler and Hopkins 1986:33). Fearful of the stigma of HIV young people learn to keep their infection secret and internalize the stigma for fear of the negative reactions. Secrecy is the response to the fear of stigma, and participants have to navigate a range of different circumstances and situations whilst keeping their secret safe.

4.9. Summary

Being told you are HIV positive is an emotional and distressing experience for young people. They have little control over the disclosure process and are dependent on the decisions made by adults. Young peoples' accounts of living with HIV include trying to make sense of why they have to attend hospital, take medication and receive treatment. Some young people suspect and guess their diagnosis before they are formally told by picking up clues and listening to those around them. Although most already know they are different, they are just not sure why, and this difference is not named. HIV appears to disrupt a young person's biography even before they are told their diagnosis; because their lives are different and have already been disrupted. Their lives are not only disrupted by a diagnosis of HIV but also by the stigma of HIV. Whilst Bury's (1982) concept of

biographical disruption in adults is highly relevant, it may be experienced differently by young people. The stigma of HIV disrupts young people's biographies differently to other life threatening conditions because the response to stigma is secrecy. Although most stories and explanations given to children are usually believed by them, some are not, and when they are told their diagnosis some feel betrayed and foolish at being lied to.

The majority of young people are told their diagnosis in hospital by a health professional with their parents present. Young people remember being told or learning that they have HIV infection as an important event because it changes relationships within families and their other social networks. At the point of disclosure a young person may discover that their mother is infected and, for some, their father as well. Although the process of disclosure may happen over a period of many years, most experience the telling as an event. The formal event of being told is usually accompanied by the advice to keep their diagnosis secret because of the fear of stigma. However, most participants are already aware of the stigma of HIV before they are told their diagnosis. Young people's reactions to disclosure vary but, for all being told changes their lives and results in a different view of self. Few participants receive support or re-assurance after disclosure, and only two or three felt able to speak to their parents(s) because they feared upsetting them. The silence and secrecy surrounding HIV continues for most even after disclosure. Participants appear to learn quickly that their HIV status must be concealed even within their immediate family. How they learn to keep this secret and 'pass' as uninfected is considered in the next chapter.

Chapter 5

Secrets and Lies

5.1. Introduction

Once young people are aware of their status, they begin to learn more about what living with HIV means. Most already know that HIV is stigmatised but they are also told to keep their diagnosis secret. This chapter explores the continuing process of disclosure after young people learn of their diagnosis. It considers how young people with HIV learn that they are different and the strategies they employ to manage this difference. The first section considers the differences a diagnosis of HIV brings, and how young people learn that HIV is stigmatised. The second section looks at the strategies young people use to manage this stigma. The final section considers the consequences of keeping secrets.

5.2. Becoming HIV- becoming different

As discussed in chapter four most young people are aware of difference before they are told their diagnosis. Attending hospital and taking medication highlights this difference and already sets them apart from their peers. However, the formal telling confirms their difference and makes clear why they are so. Some spoke about how they had changed after receiving their diagnosis.

As David recalls:

David: It was strange really, when I was told I suddenly looked at myself differently even though I had it from being born, I didn't know I had it until I was fourteen. Now I know I am HIV, it just seems to change everything and yet I am the same person, it's really weird. (aged 15yrs)

Being given a diagnosis of HIV fundamentally changes young peoples' identity, and there seems to be a process of re-organisation as an altered self is developed to accommodate the diagnosis. Despite there being no visible difference David feels different, HIV brings a different view of self. His previous view of self did not include HIV, but now he knows he has been infected all his life and his view of his past and his present have changed. Charmaz (1997; 2002) observes how chronic illness changes the view of self which is embedded in timeframes of the past, present and future. When individuals experience a disruption in their present life, Charmaz suggests that the 'past provides more than the security of familiarity, it offers a foundation for reconstructing an altered self' (1997:233). When young people are told they are HIV positive their past is altered and the familiarity and strength that can be taken from the past is not possible.

Jonas: It was a very difficult time because up until then I was fine, life was good with my friends and stuff, but then when I found out, being around my friends, I just felt a bit weird, that I had this virus and I hadn't known for all those years. It's complicated because I've still got the same friends, but just with this real hidden secret and it's.... (silence) I sometimes feel quite upset, excluded and like sometimes I wish it was different and I could go back and change everything.
(aged 16yrs)

Jonas re-assesses his past because it was not what he assumed it had been. As well as reconciling his past he has to deal with the present. Although his difference is not visible to others, it has to be kept secret and as a result, HIV has separated him from his friends. A diagnosis of HIV changes relationships for young people and their perception of themselves (Fernet et al. 2007; Lyon and D'Angelo 2006). They experience the loss of openness that may have been present in friendships before and have to re-arrange their relationships (Bury 1982) now that HIV is part of their identity, but a secret part.

Jahia: There are lots of differences to the person I was before I found out and the person I was afterwards, in a positive and negative way, cos I'm less

stressed, I'm more like I know who I am, like what I am about and stuff. You grow up quite a lot actually, and you become more mature and serious.....think about some of the big issues. (aged 15yrs)

Being told the 'truth' has helped Jahia, his view of self is clearer now he knows his diagnosis. Disclosure forces change and is the marker of an altered identity (Charmaz 2002). Like Jahia, most participants describe how they consider the 'big' issues in life more than they had done previously. Their lives are no longer carefree because HIV has disrupted them and introduced the possibility of death and a limited life expectancy (Bury 1982; Charmaz 1997; Fernet et al. 2007). Similar responses are found in studies with young people with cancer where they report thinking about serious issues such as the purpose of their life and death, because their condition has made them face the possibility of their own death (Kyngas et al. 2001; Van Donegan-Melman and Sanders-Woudstra 1986).

Young people adjust to the disruption of HIV in different ways:

Ruth: It isn't at all a death sentence, it's like a condition really, like something like asthma, something like diabetes. Some people have, you know, just something that you just live with but it's not something that going to take over your life, it's something that's there, like your right leg. So you live with whatever you've got. I think that's what it is being as normal as everyone else. Not feeling different, that's the thing, because people don't seem to like being different, everyone wants to be the same and not being outcasts. (aged 20yrs)

Ruth's view of HIV as embodiment reflects the potential of HIV to dominate her life. She has experienced poor health and numerous hospital admissions and has struggled to have what she describes as a 'normal' life. Young people fear difference because it can result in rejection and exclusion.

Participants' feelings of difference also occur within the family. Matthew is unsure if his extended family is aware of his status, but he suspects they know:

Matthew: Something in their eyes, like a leper, like you're the leper of the family....I don't quite fit in, so I mean I always try and do try and relate to them, like I ride a bike with my uncle, but I can always sense he treats me a bit, not deliberately differently, I know he, it's not that he doesn't like me, I'm sure he does like me, we have some great laughs, we really do, but it's just a little different relationship compared with the others. And that's why I think they know, and that's another reason why I've not let anybody else know I have the disease 'cos I don't know if it's true, but I feel I am treated that little bit differently. I don't want to be, I'm just normal, Matthew, look at me, I'm fine. (aged 18yrs)

Matthew no longer feels he fits in the family and although he is unsure whether his uncle knows, he believes HIV has changed the family dynamic. Matthew experiences 'felt stigma' within his own family, that is 'a stigmatised person's sense of internal shame and fear of persecution' (Scambler and Hopkins 1986:33) and this inhibits his ability to check out who knows what. As Herek observes 'Felt stigma motivates individuals to pass as members of the non-stigmatised majority' (2002:595). His use of the word 'leper' conjures up powerful imagery, similar to Ruth's use of the word 'outcast'. The use of these terms infers being set apart because of something infectious, such as leprosy, which is undesirable, and historically thought of as contagious (Sontag 1989).

As well as reflecting on difference participants identify the strong desire to be 'normal'. For example Emily states:

Emily: I think it is quite hard cos you know when you are a teenager you're just like struggling with a whole load of other stuff. Even if you don't know it at the time and then you're given that as well (HIV). It kind of sort of rearranges all your thoughts to something else. So you're like, 'Oh I can't do that anymore and I can't do that' and it's like to start with when I found out I had it I was like, 'Oh I'll never

have a family now' and sort of 'Never get anyone to marry or anything' and it's just sort of quite hard cos you're like, you'll be single for the rest of your life...and never be normal. (aged 17yrs)

A diagnosis of HIV brings loss for young people. The loss of 'normal' milestones and relationships act as markers of difference. Emily is required to develop a new future biography that has to incorporate the losses brought by HIV. Although Emily's direct talk is around normality, the message is about feeling different. As well as demonstrating difference, young people's narratives also reveal they know HIV is stigmatised and how they learn about HIV stigma is considered next.

5.3. Learning about stigma and HIV

Whilst participants are aware that HIV is stigmatised, how they become aware of it differs. For example, Amy notes:

Amy: I knew I had a disease that could kill me and make me different from everyone else, I know it don't make me stand out to them, but it makes me stand out to me. (aged 18yrs)

The invisible stigma of HIV separates Amy from everyone else. Goffman (1963) observes that those with invisible or 'concealable stigma' feel 'discredited' even though others are unaware. Amy displays what Scambler and Hopkins (1986) describe as 'felt stigma'. They observed that actual discrimination need not occur for stigmatized people to suffer as a result of their status. HIV restricts participant's behaviour and can limit their opportunities for fear of felt stigma. Young people experience stigmatisation in relation to others, and HIV related stigma is as much a reflection of 'others' as it is central to the experiences of the young people themselves.

Sarah views HIV differently:

Sarah: HIV is just part of who I am, I wouldn't be the same person without HIV,
HIV has made me who I am. (aged 23yrs)

HIV has become her 'master status' (Goffman 1963; Charmaz 1997; Frable et al. 1990).
Sarah perceives that HIV has defined and shaped her life experiences and her identity.
HIV also has become a 'master status' for Paul and Alica:

Paul: HIV and me, we have just sort of grown up together, we have grown
together..., it's always been there, I've never know anything different have I?

HIV is just part of me, I never been without it, so it is me, isn't it?

(aged 24yrs)

Alica: I've had my whole life to grow up with it and I know I'll always be with it.
(aged 19yrs)

Paul and Alica describe HIV as a central part of their identity and their master status,
however young people learn that because HIV is stigmatised it means it has to be
concealed.

As Becka and Jina recall:

Becka: I sort of realised early on that it had a stigma it did, and 'cos I was always
told not to tell anyone, and nobody ever talked about it..(aged 17yrs)

Jina: After I found out it worried me a bit cos I thought, oh if people find out I'm
gonna be bullied and stuff, but nobody ever found out so it was ok. (aged 17yrs)

The stigma of HIV is managed by keeping secrets and keeping quiet. This silence starts
before disclosure and continues after reinforcing the realisation that HIV carries a stigma.
Frable and colleagues (1990) found that those with a concealed master status tend to
focus on what people are thinking and on managing how to keep their status hidden
(1990). The 'felt stigma' participants describe is managed by silence to enable them to

'pass' as uninfected. Successful 'passing' reduces the likelihood of being the target of discrimination, but also significantly disrupts young people's lives and creates the stress of having to maintain cover (Goffman 1963).

Several participants described the influence of their mother in learning about stigma and HIV:

Jina: My mum said she hasn't really told anybody because then if like some people might react badly and so....but I always knew that ' cos everyone's just talks badly about it so..like they talk on telly about like HIV and AIDS and stuff as though it's a bad thing to have and stuff...about everyone gets shunned for it. Sometimes with like really really close friends like they've told me like secrets and I've wanted to tell them my secret but then I thought 'No'. (aged 17yrs)

Jina has adopted her mother's approach in dealing with the concealment of HIV. Living in a family where HIV has always been present most participants appear to look to their infected parent(s) as role models and learn about how to live with HIV from their parents' experiences. However parents' motivation for concealment may not be solely about the stigma of HIV. Issues such as fear and anxiety about the future, or the need to protect their family from being hurt or harmed may also motivate concealment (Waugh 2003; Lee and Rotherham-Borus 2002). But for some there is a legacy of secrecy that is passed from one generation to the next, as Jina recalls:

Jina: My mum said you don't need to tell anyone, it doesn't help and she said that it is nobody's business. I listen to her cos she has lived a long time with it and I guess knows what she is talking about.

JD: Has she told anybody?

Jina: No, no-one knows.

(aged 17yrs)

However not all participants follow their parent's advice:

Louisa: My mum had told me 'Don't tell anyone like unless you really feel you should, or unless you really feel the need to, so like keep it to yourself until you're going to get married and you have to tell your husband or something like that' and I said 'OK', and I thought to myself, 'No' I am not going to do that, it's not that I shouldn't listen to my mum, I thought do you know what, this is my decision also. (aged 18yrs)

Louisa, like all participants demonstrates agency in her decision of whether to conceal or reveal her status, however, she changes the pattern of disclosure in her family by deciding to tell. Michaud and colleagues (2009:356) found that biological parents, especially HIV positive mothers, were influential and insisted on not disclosing the young person's status for fear of stigma. Whilst not all participants articulated the influence of their parent's experiences about the concealment of HIV, several spoke about their 'instinct' in relation to knowing it was not good to tell people, as Andrew recalls:

Andrew: They said when they told me about it that it was not good to tell people, but I sort of knew as well, you have that instinct, but they did insist that it was not a good idea to tell people, as they may not be kind. (aged 18yrs)

Where this 'instinct' comes from is not clear, but may be developed through listening to the variety of messages and representation of HIV from the network of people around them, as well as wider cultural discourses.

Sarah: They did say it's not a good idea to tell people and stuff and I knew as well, you know, you just have that instinct, but they did insist it was not a good idea to tell.

JD: Where do you think that instinct came from?

Sarah: Just from the prejudice in our society, just you know even though it's an illness, like cancer and other illnesses, it's just this one is just seen as like, really upsetting (laughs) yeah, people really view HIV in a different way.

JD: Why do you think that is?

Sarah: Cos they think you can easily contract it but, that's not the case, you can't easily contract HIV, people still have that perception of basically if you share the same glass or something or use the same toilet seat and stuff and I do try and put myself in other people's shoes and I can see where they are coming from, especially if you don't have a friend with HIV or don't know anyone who has HIV the only information you are getting is from the media and then yeah I can see why people are prejudiced, I don't blame them for it. If people were to have a friend or relative with it they would be a bit more understanding. (aged 23yrs)

Sarah links the stigma of HIV with the fear of infection by social rather than sexual contact. Herek (2002) observed an increase in people overestimating the risks posed by social contact from 1990 to 1999. He found more people in 1999 thought HIV could be contracted by sharing a glass, being sneezed on, or using the same toilet seat than in 1990 (Herek et al. 2002). Other studies have revealed similar findings (Lentine et al. 2000). Stigma appears to be greater where the condition is thought to be incurable and fatal, as with HIV (Herek 2002). Participants also explain and link the stigma of HIV with other factors.

As Matthew and Becka reflect:

Matthew: I wish there wasn't so much stigmatisation about it, unfortunately because it's related to sex, because it's related with homosexuals and black African Americans and you know, Africans and Caribbeans that kind of racial stigmatisation is still there and I suppose that's partly entwined with how people see it that annoys me. (aged 18yrs)

Becka: HIV, it's not understood, I'm guessing because of the sort of huge epidemic it was and it does have links to drug addiction and sort of gay sex and

stuff and things which are still taboo. And because of that people appear to think, how come it came about in your family or something, or what has she done, and sort of links to a way of life which is, has not ever been part of my life and it comes with a lot of preconceptions and the sort of stigma around it..I'd like to be honest about it but society just at the minute won't let me...I mean hopefully in the future it will all change.. but it shouldn't be like that, but it is..(aged 17yrs)

The social discourse on HIV/AIDS has developed into a moralising discourse possibly because of the association with sex. Herek (2002) suggests that where linked to an 'undesirable condition' the stigma tends to be more intense when the individual is thought to be to blame and is perceived as having contracted it through avoidable behaviour, especially behaviours that evoke social disapproval. As Herek observes 'Such an illness tends to evoke responses of anger and moralism rather than pity or empathy' (2002:596).

Becka's belief that society will not allow her to be open about her status reflects the power of the fear of stigma, and the belief that society rejects those with HIV. Becka associates HIV with gay sex and drug addiction and expresses the assumptions that she believes others would make if they knew her status. These include the questionable moral status of her family and herself, the behaviour and lifestyle that are presumed to accompany HIV. This moral link is made by many participants. As Sontag (1989) writes 'Getting the disease through sexual practice is thought to be more wilful, therefore deserves more blame' (1989:112). Sontag observes that illness such as cancer and AIDS have often been interpreted in terms of good and evil, virtue and vice, punishment and innocence rather than as amoral biological phenomena. This moral dimension to HIV is important to participants who do not want to be labelled or linked with what they define as taboo behaviour or sexual practices.

As Neema reflects:

Neema: Like if you had it you might be a slut or something or you might be gay or whatever, it's just associated with bad things, like if you've got it then you're a bad person. I found that as well. (aged 17yrs)

Young people internalize the stigma of HIV. Participants experience stigma in relation to others and where HIV is viewed as 'bad', they feel they are also 'bad'.

As Sarah reflects:

Sarah: It's all that stuff back in the eighties, you know how, a lot of Africans have it and you get it from gay people stuff, it's always been associated with people who, gay people who may be a bit loose, heterosexual couples who, it's always been associated with things in a negative way..... I think everyone is just scared, yeah that's the main thing everyone is just scared- cos when you have HIV you die sooner than most people that's basically it. (aged 23yrs)

The route and manner of their infection matters to participants on several levels and will be explored further in chapter seven, but it is important to these young people to separate themselves out from those who have become infected via what they perceive as more stigmatised routes. Participants suggest a hierarchy of routes of HIV infection, with those perinatally infected seen as morally blameless in comparison to those who 'brought it on themselves'. Some young people spoke about wanting to distance themselves from those who acquired HIV in a different and 'less desirable way', such as through gay sex or intravenous drug use as they were perceived as the most stigmatised. Herek found that Gay and bisexual men are more stigmatized than heterosexual women. Those who have multiple sexual partners or share needles receive the most negative responses, and those who were infected through receiving infected blood products the least negative responses (Herek and Capitanio 1998).

Young people find the association of HIV with stigmatised groups difficult as Elijah explains:

Elijah: Stigma, stigma disgusting. That's another thing that just made me want to switch off from the whole HIV thing innit. The whole stereotype and the whole stigma of it like, it's worse than being gay or anything like that, if you've got cancer it's ok, if you've got a kidney problem it's ok, if you've got HIV well, wow it's the worst...

JD: Why do you think that is?

Elijah: Because of the media and the lack of knowledge and the lack of education. I mean in the world generally innit and the way they perceive and talk about HIV like you can't do it like that. Cos people get the wrong idea and it's the way they put the statistics across and it's the media that's doing it, it's them man. And there's people with attitudes like when people don't know about something they're scared of they just ignorant innit. I'm not being funny, it's sort of all communities but the black community in particular, the whole thing about gay people and not liking gay people and holding hands with gay people. I mean it sounds so stupid, I get so angry when I hear it but literally you hear people like 'If you are HIV you're gay' kind of thing, like whoa, how flipping ignorant are you, are you for real.. if the stigma weren't there the obvious thing like you would just kinda getting on with things innit. (aged 20yrs)

In Elijah's community having HIV is synonymous with being gay. The representation of HIV as predominantly an issue within the gay community excludes Elijah and risks stigmatising him twice. Elijah does not see himself represented in society as an HIV positive heterosexual black young person.

This stigmatisation leads young people to want to differentiate themselves from 'others'.

Alica describes how she explains her infection:

Alica: I say I've always had it. I was born with it. It's not something I got, I think that swayed my current boyfriend the fact that it couldn't be helped with me. It's

not something like I went out and got drunk and had unprotected sex with someone and caught it, or did drugs or stuff. It's cos I was born with it, and I think that's where they are sympathetic and understanding...otherwise I don't think he would have stayed with me which I can understand..(aged 19yrs)

Alica is keen to separate herself from those who engage in 'risky behaviour'. Her extract reflects the moral judgements that many participants observe and criticise, but also colludes with the view that blames people with HIV because they must have done something bad. This illustrates how participants internalise and perpetuate the view that acquiring HIV via sex or drugs is less morally defensible. Alica believes she has to demonstrate her innocence, and this is done by distancing herself from those 'others' who are to blame (Joffe 1999). The 'othering' of HIV enables participants to pass the 'blame' and free oneself from the stigma associated with HIV. Gaining a positive sense of identity through comparison with negatively valued groups is common (Joffe 1999), and participants do not want to be associated with those that are to blame. The fear of infection that accompanies HIV also intensifies the need to draw a distinction between 'them and us', because as Herek (2002) suggests, greater stigma is associated with a condition when it is perceived to pose a risk to others. Joffe observes 'Mass, incurable illnesses, from syphilis to cholera, from the Black Death to leprosy, have been linked to the 'other' both historically and cross-culturally' (Joffe 1999:26). How young people learn that HIV is stigmatised is a complex process, but one of main influences they identify is the media representation of the condition. This is considered next.

5.4. How the media do HIV

Whilst young people may draw upon their existing knowledge of HIV, how HIV is represented in society contributes to how they make sense of the new part of their identity. They identify the influence of media such as television, film, and newspapers and view these as reinforcing restrictive and negative images of people with HIV.

As Matthew, Neema and Becka observe in the following extracts:

Matthew: There's not even a good film about someone with HIV, well Philadelphia, but deals more with social homophobic issues more than HIV, well it does deal with HIV but if it was a straight man it would open up a lot more possibilities. I feel bad even saying that. (aged 18yrs)

Neema: When you see HIV in the papers or on the TV you just see people in Africa and they're all sick and people don't really think about HIV here in the western world, it's all just about Africa or gay people (laughs), not about people like me...(aged 17yrs)

Becka: People making jokes about it like in programmes like South Park and, people have quite, I don't know it's hard to think of the word, but you just.....they make light of it but are also sort of completely horrified by it at the same time. Like when I was in Biology class when the teacher was asking questions and I just knew a lot of the answers and I was quite shocked how little people knew about it and it was the realisation as I got older that it was relatively new and it was the sort of eighties. Cos I always thought it had been there, but it hadn't. (aged 17yrs)

Young people do not feel represented in the media coverage of HIV although they view the media as highly influential particularly with their peers. HIV is mocked in the media as well as presented as something to be feared. Participants described being shocked at the inaccurate information in the media which they see mirrored around them. As expected, most HIV positive young people have a greater knowledge and a heightened awareness than their peers. Becka's extract reinforces the fact that most of these young people have never known a time without HIV.

Positive role models appear important to young people as they frequently spoke about feeling excluded, marginalised and unrepresented in the public discourse on HIV. This may be connected with the lack of positive role models. A successful adult living with HIV provides an example of a future with hope and possibility of achievement.

As Matthew and Ruth reflect:

Matthew: I wish there was more people you know, like Kylie Minogue, how she's dealt with cancer and if you had someone you know, and then there was Des Smith, the cabinet minister he had HIV, but there's not really anyone you could look up to.. and you know, you know you've got a future, but that's sort of frustrating and there is no like role model to look forward so you know that 'Oh I can look that far, I can get that far, be that person....(aged 18yrs)

Ruth: Maybe more people should speak up, but I can understand why it's hard because I mean I wouldn't be able to speak up, I couldn't. But I mean more people should speak up. So you can see examples of people that are successful, examples of people that are living a dream life, but with HIV. I think a lot of people are not seeing that, they think people with HIV, got no jobs, got no relationships, look ugly, don't know how to do this, can't talk, whatever, and I think that's a picture of what a lot of people are saying I think, but I feel that is a big thing in education. (aged 20yrs)

Participants want to see those with HIV represented as successful. Ruth perceives those with HIV as silent, in that they can't talk and are not heard, which accurately represent her position. Giles and Maltby (2004) found that celebrity role models provide a secondary group of 'pseudo friends' for young people in their transition to adulthood. These young people feel excluded from this process because there are no role models that are HIV positive.

Young people infected with HIV in the UK are embedded in a culture that stigmatises the condition through media representations and the attitudes they observe and gather from their peer group. Their peer group in turn reflects the prevailing culture of stigmatisation in the media and within their communities. Learning that HIV is highly stigmatised forces young people to develop strategies to manage the stigma, these strategies are considered in the next section.

5.5. Strategies

Young people engage in two main strategies to prevent others finding out they have HIV, they keep secrets and they lie. Participants describe having to manage and control information about their HIV status in a range of situations; in the family, at school, with friends and, for some, in sexual relationships. They learn to conceal the different aspects of HIV, such as taking medication, attending hospital, being ill, and the need for protected sex. How young people conceal their status differs, but all engage in secrecy and lying. Participants' differentiate between secrecy and lying. Secrecy is a continual process they engage in on a daily basis. Lying is deliberately deviating from the truth and is usually focused around events or circumstances.

'Keeping my head down ' – Managing secrecy

Participants engage in secrecy in a variety of situations including within the family. Despite the family being the one place where at least one person knows a participant's status, some participants still have to conceal their status from other family members. Goffman (1963) identified how those with 'concealable stigma' can 'pass' unnoticed and avoid being discovered as having a stigma because it is not visible and therefore can be easily hidden. Young people collude with their mothers to pass within the family as uninfected. In families with siblings (including half and step siblings), 60% of participants' siblings were apparently unaware of their own or parent's status. But one cannot assume from this that they are necessarily unaware, especially given that HIV was rarely openly discussed or acknowledged.

On their return home from being told about their diagnosis many participants did not talk much within their families. For some this may just be part of their family culture, but others felt the subject was avoided:

Ruth: We don't really talk about it too much with my mum at home, but I mean because of the fact that my mum's also got the virus and no-one knows of my mum's virus and no-one knows about mine. It's only between me and my mum.

JD: What about your sister?

Ruth: My sister doesn't know either, no-one knows about it, it isn't ever brought up at home, because if my mum wanted to tell her she would, she must have thought I needed to know and she didn't...but maybe she hasn't told her 'cos she wants to forget herself.. (aged 20yrs)

Participants are expected to keep secrets within the family and this creates disruption in family relationships. It is identified as a major theme in similar studies of children with cancer (Van Dongen-Melman and Sanders-Woudstra 1986). It appears more common where a young person lives with their infected mother wherein the young person is expected to keep secret both their own and their mother's diagnosis. The sharing of the virus between mother and child creates a connection that bonds them, but also sets them apart from other members of the family. This connection carries an expectation that the secret will not be shared.

Ruth: It's just mum and me know, my sister doesn't, I don't know if she suspects, I share a room with her and have to hide my medication in the bottom drawer. If I was her I would notice and have a nose about, but she doesn't do that,if I was my sister ..I wouldn't be happy. I'd kind of feel like I am not being trusted or I am being excluded.... In my position I think I would want my sister to know.... I do want her to know in a sense that I want her to know that she's been trusted and she knows the position and she knows what I am going through.

JD: Do you think she may know?

Ruth: Possibly... I've had quite a few illnesses which have probably been HIV related, I've had shingles and the way my mum has treated me, like my mum's

treated my sister differently. My sister at the moment thinks that my mum probably favours me, but I see from my position it's not. It's like because before medications had first come around my mum was very peculiar about me going out anywhere just in case I catch illnesses off anyone, and my sister was very different. She let her do anything and it was very over protective towards me...

I felt that my mum kind of spoilt me a bit in the sense that because medications weren't around and she wasn't sure they were going to find medications...she didn't do the same thing to my sister. I think that was all my sister can see and she probably didn't understand why and I think that was more guilt from my mum's side. I don't mind telling my sister but I know that if I tell my sister that's where my mum comes in, and my mum obviously has her own reasons for not telling my sister 'cos she's going to ask a lot more questions than I have 'cos she is older and because it happened while she was alive...I don't want to upset my mum so I choose to like leave it as it is, I would like my sister to know but there's another person involved as well. (aged 20yrs)

Secrecy about HIV appears to have a double effect, in that it can isolate and exclude the young person infected from siblings, but also excludes and isolates the uninfected sibling(s). Participants describe not talking with parents for fear of upsetting them and this is commonly reported in studies with older children with cancer, where they remain silent in an attempt to protect the adult (Bluebond-Langner 1978; Chesler et al.1986; Share 1972). Young people express strong feelings of loyalty to their infected mother or other infected family members. However sometimes young people decide to tell their siblings:

Sarah: My parents didn't tell my brothers and sisters, which was hard, they still haven't told them. I told my big brother when I was 15 and he was 19, he was just persistent in asking why I was taking so many tablets and stuff, and I just got tired of hiding and lying, I said they were vitamins, but he wasn't silly, he knew

something was wrong and I eventually decided to tell him, and he was fine...(aged 23yrs)

The desire to tell a sibling can be strong and can result in greater support for the young person. Where participants have told their siblings, they describe them as a great source of support. Sarah has not told her two younger sisters yet, and has managed to keep her status secret in the family since she was nine. This may be because her sisters are younger and her brother is more able to offer her support in the family. Studies with siblings of children with cancer have found striking similarities in the emotional distress between those with cancer and the healthy sibling, such as social isolation and increased anxiety (Spinetta and Maloney 1978).

The family is the one place where the participant's status is usually known at least by one person, but maintaining secrecy at school is identified as particularly precarious and no participant reported telling anyone in secondary school – including teachers - despite many having regular absences. Most spoke about experiencing difficulties particularly in sex and relationship education lessons where HIV was discussed, where they felt there was a risk that they may be exposed and feared disclosure. Participants develop strategies to keep their status secret and manage the fear of disclosure by trying not to draw undue attention to themselves, and be continually alert to possible circumstances that could risk disclosure. This demands mental energy and agility to be able to deal with and respond to potentially dangerous situations where your identity risks being exposed. In the following three extracts Becka, Alica and Louisa describe how they manage to 'pass' (Goffman 1963) as uninfected at school:

Becka: There was one time in economics we were talking about HIV and I didn't know whether to keep quiet and if I keep quiet does that mean Oh! I might have it, but then if I say too much, so I must have HIV and stuff like that, so I was trying not to be noticed, or let anyone get suspicious, it was real dodgy time. (aged 17yrs)

Alica: When the topic did come up, because it did occasionally come up, I used to sit there and I used to think, 'Oh my God, do I have a massive sign on my head that says I'm HIV positive?' Because I wouldn't say anything but I'd feel so self conscious and I'd feel like everyone knew right at that moment kind of thing (laughs) and it was weird and I didn't like that actually. I sat there very quiet, head down and didn't say anything (laughs) cos I wouldn't own up, because I knew they weren't specifically talking about me, I thought 'Well maybe they could have found out some other way, and I hadn't hid it well enough (laughs) yeah I felt weird..(aged 19yrs)

Louisa: There was one point when I thought 'Oh God, everyone knew' I don't know what it was, but I just thought, 'Why is everyone looking at me?' I began to feel paranoid. I thought 'Oh God, everybody knows', you know, is it something to be ashamed of you know, and something to impress and tell people, and then I thought, 'No, don't tell no-one, just sshh'. (aged 17yrs)

For fear of being found out participants engage in behaviours to minimise suspicion and unwanted attention. Charmaz (1997) observes that concealing illness often takes an enormous amount of work, and keeping it secret avoids both disclosure and distance from the illness. 'Passing' as uninfected involves trying to become less visible for Becka and Alica who perceive their stigma is highly visible to others. Louisa's internal debate focuses on whether HIV is something to either be ashamed of or used to impress. HIV is linked to shame because people perceive those that are infected are to blame for their own infection, as previously discussed, but using an HIV diagnosis to impress is different. Telling people may gain attention for Louisa, but it may be a desire to shock or help her stand out from the crowd. However young people learn to manage secrecy, they appear to develop the ability to conceal their status over many years. The next section considers how they learn what to do.

‘Learning the rules’ of secrecy

Learning to keep secrets is a skill these young people acquire from an early age. They describe how they develop this skill in many different ways.

Elijah: I knew what it was, I knew it was bad.... and that it was secret, those are the rules I knew it, that was just normal to me, that was normal. (aged 20yrs)

Elijah’s extract does not make it clear how he learnt the rules or who told him, however later on in the interview he explained:

Elijah: I knew the code, I knew the code, it’s all about a code innit, a code of silence and I adapted to that lifestyle at school even without knowing like. I knew when to speak about it and knew when not to speak about it kind of thing innit.

JD: And how do you think you learned that?

Elijah: Because I did hear about how people talked about it innit. When people were saying ‘HIV err are you HIV, you got AIDS err, err,’ this was like primary school times like you know what I’m saying. So I’m really sitting on a field, and thinking about how I see it on TV and that ‘cos remember the Mark incident?

JD: Oh in Eastenders, yeah I do

Elijah: I was thinking of all that, I saw all that so my eyes was open innit. So I was aware innit in that sense like. Don’t talk about this with people who don’t know about it, ‘cos it ain’t normal innit. (aged 20yrs)

Participants learn what is expected and strategies from watching and listening to others. Elijah learnt from the silences as well as the talk surrounding his condition. He observed that HIV was not talked about and that it was kept silent, so deduced that they were the rules. Like other participants’ he identified how television influenced his view of HIV and the negative way it was portrayed. He recalled Eastenders, a BBC 1 soap, where a character Mark Fowler, was HIV positive. The storyline included a range of reactions to

his disclosure, which reinforced his decision to keep his HIV status secret. Whereas secrecy had become 'normal' for Elijah, other participants found it more difficult to manage:

Jamelia: Keeping secrets make me feel small, I guess carrying a secret round really is the hardest bit..I've not told no-one. (aged 17yrs)

Jamelia expresses her difficulty with deceiving others and keeping secrets. Some participants found keeping secrets gave them control and agency:

Alica: Not telling was just like having, it was just for me, it was just my chance to be like everybody else. I didn't have to put on an act or anything like that, I just, you know, they didn't know because I chose not to tell them. And that was my decision at the end of the day, so I could just be me...(aged 19yrs)

Mark: It's easy to keep it to myself, I find it very easy, but, even I would keep it from someone who is HIV positive, I know friends who are HIV positive and would never tell them my secrets. Cos it's none of their business, that's how I see it, I am a secretive person I don't tell and tell no-one nothing about my status, until I can trust you 110% I will not tell you regardless of whether you have got it yourself. (aged 18yrs)

Keeping secrets for some participants was easy because it enables them to 'pass' as 'normal' and continue to interact with friends and their established social networks. HIV does not disrupt social relationships because nobody knows. HIV becomes part of their hidden identity and a different world that they can distance themselves from for a while. Some participants' find containing HIV within the hospital easier:

Ruth: Cos for me during that time .. my mum protected me very much. I didn't really talk about it. I wasn't going to stand out. I didn't talk about it for about four years. I only thought about it when I went to the hospital. So HIV started when I walked into the hospital and when I walked out that was it. So that didn't affect

me much, because at home mum didn't talk about it so much, and at school it was never addressed and people never knew so that was it. (aged 20yrs)

Goffman (1963) refers to the health care staff as 'the wise' who protect and keep a person's secret. HIV does not appear to occupy a central part of Ruth's life outside the hospital, she restricts and controls where HIV impinges. If Ruth does not discuss or acknowledge HIV she is able to control its effect, and distance herself from it.

Keeping HIV secret is also motivated by other factors as Samuel explains:

Samuel: It's better for them not to know, cos it make it easier for them to deal with me because if I told them some people would feel uncomfortable and they would always be trying to be very cautious with everything they do and(silence) avoid me. (aged 19yrs)

For Samuel, keeping HIV secret protects his friends and enables him to continue life with them without the risk of rejection; his accepted identity without HIV remains intact. Keeping an HIV status secret is difficult for many young people, but some find it easier than others. However most participants find lying harder and this is considered in the next section.

'Lying is different'

Young people differentiate between keeping secrets and telling lies. Lying means constructing alternative stories that deliberately deviates from the truth to explain events linked to their status, such as illness, hospitalisations and health problems.

Tessa: Keeping secrets, it's just kind of normal, but it's weird, I reckon, it was weird in the beginning, but because it's become so normal now I don't think nothing of it, but lying is a different matter. (aged 19yrs)

Carmel: Keeping up with your lie and it's like, even though I am dead good at acting, it is real, and I'm no good at lying, as you can tell when I am lying, that's

why it's better when I lie over the phone, but when you're lying to your friends you really just do have to kind of know the story, lying to someone's face, now that I hate. (aged 18yrs)

Young people find lying to friends particularly difficult because they feel they are betraying their trust. Being proficient in storytelling is essential to avoid being caught out if the stories are inconsistent friends will notice. Participants avoid lying face to face because it is hard to hide your feelings when you are looking at someone. Concealing an HIV status is seen by participants as a necessary survival mechanism in what is perceived as a hostile environment, and keeping secrets becomes part of a 'normal' life, a sensible and defensible response to the situation. Lying however is seen as something that requires a positive choice plus an active decision. Most young people are not happy to lie, but spoke about the struggle to both understand and defend their behaviour. Despite lying to friends for many years, it remained uncomfortable, and something that most young people spoke about wishing they could change.

Lying becomes necessary when participants are unable always to hide or conceal their illness. The need to explain absences and find a credible illness and cover story requires telling lies.

Samuel: Hardest bit is like keeping it, like for some people, cos you can't always hide it you know. Especially with medicine and everything for example somebody will ask, that's the difficult part cos you live now somehow like a lie, and you have to come up with things and tell them. Sometimes I say it's vitamins or the worst part was once I was admitted to hospital, you know 'cos people ask 'Where have you been?' I said I had ulcers.

JD: How was that?

Samuel: It was if by some chance somebody gets too inquisitive or the person has somebody who was once sick with ulcers then you pick such a thing how are

you going to back it up, 'cos I didn't know much about it, but I just took ulcers because I had some problems in my stomach so then it was easier. (aged 19yrs)

Selecting a good cover story that is both believable and sustainable is important because if it is challenged, participants need to have some information to 'back up' their story. Participants reported lying to explain short absences or such things as medication, easier than lying about longer term absences, such as hospital admissions. Some participants develop complex stories:

Elijah: It's like this whole double life business man, it's the whole double life thing... It's crazy man, it's crazy, that's what I'm saying...because I used to work and stuff and then I stopped working and that I had to come on benefits and that. And that money is used to live innit, but to explain that I'd just be like, 'Right I sell drugs innit, like, I go to the country innit like', so that would explain my disappearances innit. So the time when I was in here for like two months they thought I was in the countryside like making money so..

JD: And how did that make you feel, telling them that?

Elijah: Ah, believe what you want to believe innit. I know what I'm doing, I hate all that lying. That's disgusting man. That's just filth man, like not telling your friends. I didn't tell me friends what's really going on like 'I'm sick, I'm in hospital, come and see me' like that time you really need your friends, you needed support and can't even tell them that. No-one coming into see me and I'm sitting there dead in the bed like dying literally like none of them will see me again kind of thing innit. But it's just the fact of the matter that I haven't got to explain anything to them innit. I'm going through nothing, it's a bit of relief in that sense innit. (aged 20yrs)

Living a double life is not easy for participants like Elijah, and trying to find a credible cover story that satisfies friends to explain an absence of several months is difficult.

Goffman identifies the difficulty of a 'double life' with 'those who think they know the whole man and those who 'really' do so' (1963:98). Concealing a stigma affects long-term relationships more than it does short-term interactions. Smart and Wegner (2000) found that those leading a double life, although they seemed at ease, experienced a pre-occupation with their stigma. The consequences of lying can be isolating and stressful for young people. Studies with gay and bi-sexual young people report similar stresses at leading a double life where they keep their sexuality hidden (Carragher 2002). At a time when Elijah needs friends to visit and offer support, he cannot tell them the truth, and consequently spent a lonely two months in hospital. Yet whilst highlighting the difficulties connected with lying to friends, he identifies the relief of not having to explain. Lies may isolate Elijah, but are seen as necessary and helpful because they also protect him and his secret.

Jacob: Lying is like a shield, it protects me like, it's like a protective shield, I don't like but it keeps me safe.. (aged 18yrs)

Concealing the stigma of HIV protects participants from disclosure however difficult it is to manage because it enables them to participate in social life without fear. Where participants can control social situations by hiding an HIV status, they can control the information about HIV and avoid the consequences of disclosure. Goffman (1963) observes how when young, parents protect a child who has a concealable stigma within a 'protective capsule'. Jacob has constructed his own protective shield and is therefore able to 'pass' as normal and function as someone without HIV.

Participants also spoke about having to extend their lies to include their family's HIV status. As Paul recalls:

Paul: I didn't tell people what my brother died of when they asked, I just lied, well, it was partly the truth, he did die from a lung infection, but it was caused by HIV. (aged 24yrs)

Lying about the cause of death is difficult for some participants as it reinforces the stigma that is attached to HIV, and reminds participants that HIV is treated differently and that they in turn are different. Emily reflects on the death of her father:

Emily: If he had died from cancer I would have got loads of sympathy and people would be kind, but with HIV you can't even tell people the truth. (aged 18yrs)

Participants describe lying in situations where normally it would be natural to disclose details; consequently they experience further isolation because they are unable to access the support and care that peers and others may provide at a time of loss. Keeping HIV secret in intimate relationships is particularly difficult for participants and is considered next.

5.6. Keeping secrets and lying in sexual relationships

Young people differentiate between secrecy and lying in intimate relationships and most make a distinction between long term and casual partners. Most defined a casual partner as either a 'one night stand' or someone they saw a 'couple of times', and did not disclose their status to. A long-term relationship was defined as seeing someone for two months to six months. Most participants report disclosing their HIV status to long-term sexual partners and felt anxious keeping their HIV secret in relationships describing how HIV changes relationships, Charlotte reflects:

Charlotte: Our teenage relationship just involved hand holding and I wasn't even comfortable with that, I just didn't want him to be near me just in case the books were wrong. If they got it wrong and something happened. And when he did lose his temper and asked me what on earth had changed I couldn't answer. I was told that this wasn't something that was to be spoken about outside the family. (aged 19yrs)

HIV introduces fear and anxiety into relationships for young people some of whom are just starting relationships. Some also spoke about the stresses and difficulties of maintaining secrecy in long-term relationships.

Mark has been with his first serious girlfriend for over a year and she wants to have a baby:

Mark: At the start sex was a priority, condoms 100% condoms, condoms, condoms, throughout the whole thing, but I have a stubborn girlfriend, you see what I'm saying and she is very opinionated, yeah so now we have been together six months, maybe we should stop using condoms, cos I want to have a baby with you, and you know she is not as stupid as all that, see me, I know all about the effects what will happen, she'll tell someone about me. I can protect myself, so well, I said I don't want to have a baby so we have to use condoms, then she will say 'No, let's go on the pill' then I have no excuse do I, well I say I don't trust the pill, I used that excuse now and she just goes on about not using condoms.

Basically she wants me to ejaculate inside of her, basically everything I am doing to prevent her from getting it, it's like she's trying to push me that way, so she gets infected but, I'm staying strong in that, I'm not doing that. (aged 18yrs)

Participants learn that if you share your secret with someone you have no control over who is then told. All the time you keep the secret, you have control over the information, and are able to protect yourself. Mark focused primarily on his need to protect and maintain his secrecy, because he is fearful of the consequences:

Mark: So many different consequences, one she will never talk to me again, two she might be infected and she will get very angry, three I can get arrested, and four, even if I am still with her, it will be...(aged 18yrs)

Most of the sexually active young men in this study spoke about concerns over the criminalisation of HIV. Keeping safe and avoiding passing on HIV infection is of great

concern to them. Of the nineteen (68%) participants who reported being sexually active, thirteen (68%) reported using condoms as protection when they first had sex, and six (32%) did not use condoms. Of those that have had sex, seventeen (89%) reported not disclosing their status to any past partners. However of the nine participants with current partners, seven (78%) reported disclosing their status. Participants spoke about the difficulties of having protected sex and it is these situations where they recalled lying. Lying in intimate relationships usually focuses around finding a way to ensure that sex is protected without having to tell a partner.

Denisha: Like these days boys are so like, 'No I'm not using condoms' and it's just like, they try and say, 'Ah you don't feel nothing with a condom on, you feel it more without a condom. And it's just like, 'OK', There's been times when I've had to lie through my teeth about it. If he says why I won't not use a condom, what's the point? One day I had to say, 'Oh when I was little my uncle touched me up in that way and that's why I don't like playing without a condom, so since then that's scarred me for life innit and they understood that, even though that's sort of a lie, yeah. I had to say it innit, but then maybe they will get it into their thick heads that I'm not going to do it without a condom. If that means you have to lie, then you just lie, do what you need to do, lie. (aged 18yrs)

Participants do not want to infect others and most are aware of their sexual responsibility to protect others. This may result in young people developing an intricate web of lies that they have to remember and maintain.

Matthew: If I was to have sex with somebody now, say and they didn't want to use a condom I could insist 'Well I've got hepatitis B', which it's not as bad, it's not got the stigma around it that HIV does and then they'd understand, I know it's a lie but it's OK, it's alright for our own safety and precautions. (aged 18yrs)

Young people rationalise lying in order to protect partners from infection and avoid disclosure. Whilst the fear and stigma of HIV may drive the need to lie and keep secrets these strategies have consequences.

5.7. 'I just shove it under the carpet' - Consequences of secrets and lies

Participants describe how keeping a diagnosis of HIV secret demands one to be continually on guard for fear of someone guessing or discovering your status. Although parents and health professionals may advise secrecy with the aim of protecting young people from the stigma and possible discrimination of HIV, some young people experience the keeping of secrets and lying as stressful. Some express this through anger and react against the constraints of the illness, such as Elijah, who decided to stop his medication for several years:

Elijah: It's the whole thing man, just a rebellion against the whole thing innit. Really truly I was just bitter and angry against the whole like...I never really grieved for my dad, never really grieved for my mum, I've never really grieved for the HIV. None of them. I'm a bottle, you know what I'm saying, I'm a bottle like, I literally bottle things up and find holes and try and squeeze them out. I just shove it under the carpet, and I've been doing that all my life innit. But the thing I didn't realise was it was still coming out. I was still releasing and opening that bottle up but, in different ways. Taking it out on the wrong people innit, talking to no-one...(aged 20yrs)

Elijah's anger is complex; some of it is about loss and grief, but also about the impact of what he describes 'being a bottle'. His use of the phrase 'I've never grieved for the HIV' reflects powerfully the loss that accompanies a diagnosis of HIV, the loss of a healthy self and a life he may have lived. The consequences of stopping medication for Elijah were serious as he subsequently struggled to establish himself back on medication and developed drug resistance, leading to a poor prognosis and reduced life expectancy. Of

course, the decisions Elijah made regarding his medication may have been no different even if he had been able to deal with his anger, although he does not feel this is the case.

Joanna has been treated for anorexia as well as depression, and in following extract she reflects on the effects of keeping her status secret:

Joanna: I think the bad thing is...and that's why I kind of closed into myself, like ever since I found out, I would keep that a secret from everyone, even my parents and then I'd kind of start keeping other stuff a secret so I wouldn't tell them like what was going on or what I felt or anything. So I kind of cut off from everyone, including them and that was quite hard on my mum particularly. I just found that like if I close off all the emotions then it would just never come out, which is basically I'd been told for it not to just in case cos of the way people are being talked about. That's when I started to go into the depression really, it was just, didn't want to talk to anyone, I didn't trust anyone, I don't sort of trust my parents with most things, which is obviously quite hurtful for them.

Like still sometimes I still suffer from depression occasionally and mum will try and sort it out so she took me to a psychiatrist who did not help it all and made it worse....cos in the depression I got an eating problem and my mum said I was anorexic, cos I was sick after I ate and stuff. (aged 18yrs)

The secrecy of HIV had occupied most of Joanna's life; she has developed a pattern of keeping everything secret. When participants discover they have been lied to, some find it difficult to trust their parents again. The lack of trust Joanna describes has resulted in her becoming isolated within the family and the only control Joanna has is to withdraw from those she feels betrayed her.

Other participants, such as Alica, also spoke about feelings of depression:

Alica: I went through a really depressed stage when I was about 16 and I did the whole cutting thing myself and crying all the time. Not getting out of bed and not

going to school. And I think that's probably how I kind of dealt with it, just by being really down.... I got referred to a psychologist that helped, it lasted about six months to a year. I remember it as being very dark and like lonely time of life..

I don't know what started it off....but I think I'd known for a while, you know, you're not healthy in your mind, you don't, you shouldn't be thinking thoughts like, you know, how to kill yourself and things like that..(aged 19yrs)

Alica reflects on that period:

Alica: I think it probably like because I had no-one to talk to for a long time, I had other ways of expressing my anger which would get attention and that way someone would have to talk to me, like whether it be professional or otherwise.. and I did that by cutting myself, you know the usual things, but I think it was probably down to my HIV and just feeling a bit lonely and alone. (aged 19yrs)

Participants describe the hurt and pain that having HIV brings and how alone they feel. Alica links her anger to HIV, feeling lonely and wanting attention, she felt she had no-one to listen to her, yet by self harming she was heard. Whilst Alica makes the link between feeling isolated and developing a mental health problem, it cannot be seen as a simple cause and effect. Sarah also had mental health difficulties:

Sarah: A few years ago ..I had a mental breakdown and it was the whole build up you know just thinking about your life and the HIV and the fact you're not sharing that with anyone, not having anyone to talk to, and that and then issues with my step mum and work at Uni.... I didn't really talk about my problems.. It's just keeping everything inside, in terms of my parents we just don't really talk about things.... the doctors said it's a matter of where she hasn't talked about things and things built up and things just exploded and things and her brain couldn't take it anymore, so..

JD: Is that how you felt?

Sarah: Umm, yes (strong emphasis).. I used to say a lot of things related to my HIV when I wasn't well you know..like 'you guys don't understand and I'm going to die soon' and you know just things like that really depressing things, yeah mainly related to HIV and stuff.....(silence) some, some, sometimes I think it would have helped if I had talked more about HIV and how I felt and had somebody there to talk to about it...(silence) it's mainly the family, I wanted to talk to somebody to talk to....they didn't say if there is anything you want to talk to me about, in terms of the HIV, if you are worried about anything, I'm there for you, you can talk to me, yeah..... it felt like really hard, I felt constrained like, if they (parents) talk to you about it you start to see hope, you start to see a future, but for me it's like I didn't have that, as young as I was I had to learn from living it, to get my own sense of hope, you know and I had to go through that experience.
(aged 23yrs)

Participants identify the importance of having someone to listen to them, because living with HIV is lonely and hard. Sarah connects being heard to her ability to find hope and see a future; she wants her family to listen to her, but her family is fragile and disrupted having experienced the loss of other family members to HIV. Sarah's mum had died from HIV and she was not on good terms with her step-mother. Facing the fear of dying and feeling there is no-one to share her feelings with are major emotional issues for Sarah, and trying to deal with these issues alone is distressing. When adjusting to a diagnosis of several young people make a connection between with the lack of support and the psychological stress. As Amy reflects:

Amy: It's quite important to tell someone, cos you start messing with your head.

JD: Like what?

Amy: Just starting thinking about it too much and your head will just start wanting to explode. That's how I went into depression – not like full depression like to take medication, but I just started getting depressed and started to get miserable, didn't

want to go out, didn't want to nothing things, it was constantly on my mind about having it. (aged 18yrs)

These four extracts above from female participants illustrate the complexities and consequences for young people with HIV. They manage the concealment and secrecy of HIV differently, have different support structures and networks around them, but most of their networks are with people that do not know their HIV status. For some, family structures and social networks are more limited and more fragile than others for reasons other than HIV, but HIV may add to their feelings of isolation. Families with HIV have already been disrupted, most have already experienced previous losses, with nearly 80% of participants having lost one or both parents; one participant has lost eleven family members to HIV. These young people already live in disrupted families to which further disruption is added when they are told their diagnosis. The experience of disruption to biography when an individual's life has already been disrupted is different from those whose lives have been interrupted less (Ciambrone 2001; Williams 2003). Young people have less well developed resources to draw on and as Bury (1982) observes, the key is being able to identify resources to help the biographical disruption that illness brings. Most participants link HIV with loneliness because they perceive that they cannot share an important part of who they are with people around them. As Elijah and Becka reflect:

Elijah: It hurts man, it's tough innit, everyday of course it's heartbreaking like shattering like. Like solitude, like, like I feel such a loner like I've seen it on my life like, and I've become more and more of a loner like because of the world I live in and that's how I choose to live. (aged 20yrs)

Becka: No one knows do they, all this stuff inside. She looks happy, that's just it innit, looks are deceiving. I would consider myself as the fucking loneliest person in the world...there is so much anger.. but I just keep it to myself innit. (aged 17yrs)

The identity these young people show to the world is not a true reflection of their other world with HIV; they live in a private world with hidden stigma, and construct different narratives appropriate to the situation. By maintaining their secrecy and lying they ensure others do not find out their status, but for most this is a difficult and lonely experience. Some young people linked their emotional and mental health difficulties with having HIV.

5.8. Summary

After young people are told their diagnosis they begin the complex and difficult process of finding out how to manage life with HIV. They learn that they are different and that HIV carries a stigma. They discover the stigma of HIV from listening to others talk of HIV and how it is represented within the media. Participants perceive that HIV is represented in negative terms in the media and that there is a lack of positive role models. They develop two main strategies to manage the fear of stigma focused on secrecy and lying. Whereas keeping secrets is seen as acceptable by young people, lying is less acceptable and experienced as difficult. However, both serve a clear purpose. Keeping HIV secret is intertwined with disclosure decisions and trying to control and avoid situations where possible disclosure could occur. Some young people look to their parents as role models and follow their example in keeping their HIV status secret. Their decisions are particularly influenced by a parent who is also HIV positive and whose secret they are also expected to maintain. Young people worry about lying and most find keeping secrets stressful, but they protect their parent(s) by not talking with them for fear of upsetting them.

Young people have to learn to manage the stigma of HIV and control information in order to preserve their social relationships and avoid stigmatisation. They learn quickly to 'pass' (Goffman 1963) as someone uninfected and in that way are able to preserve their social relationships. Young people keep secrets and lie within many different contexts, in the family, at school and in sexual relationships. They live with the constant fear of discovery and are on continual alert to the risk of exposure. However, in long term sexual

relationships avoiding the risk of HIV transmission is as important as avoiding disclosure of HIV status.

Maintaining secrecy takes a huge amount of emotional and mental energy and attention to detail within every social situation to ensure that no clues or information are inadvertently given that could result in being identified or suspected as HIV positive. Many young people perceive themselves as excluded from peer networks and some exclude themselves for fear of friends finding out or of being put in a situation where there may be risk of disclosure. Some young people believe that their HIV status has had a profound impact on their emotional wellbeing and mental health; in particular, participants identify the lack of someone to talk to or listen to them as significant in their experiences of depression and loneliness.

Chapter 6

To tell or not to tell – disclosing an HIV status

6.1. Introduction

Most young people in this study report managing living with HIV by keeping their diagnosis secret and controlling information about their condition but, there are some who decide to tell other people for particular reasons. Some of the particular dilemmas and risks for young people (Battle and Wiener 2002; Michaud et al. 2009; Wiener et al. 2003; 2006; 2007b) raised by disclosure will be addressed in this chapter. Participants make decisions about disclosure across their life course and some decide not to tell anyone at all. The stigma of HIV makes the decision to disclose one's status a difficult one for young people and they may hesitate to reveal their HIV status because they fear the reactions of people; but also because of the difficulty they may have in accepting their infection and their identity as HIV positive (Michaud et al. 2009).

This chapter explores the circumstances under which young people decide whether or not to disclose their HIV status. It begins by considering the dilemmas and risks identified by participants when they disclose, then considers the responses of those participants who decide to tell and those who do not. The final section discusses the effects and consequences of disclosing a stigmatised identity and how this alters young peoples' view of self.

6.2. 'I don't know if I should tell' – The dilemma of whether to tell others

The decision whether or not to reveal their HIV status is fraught with difficulty. Goffman (1963) suggests:

To display or not display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where?

Goffman 1963:42.

Louisa's dilemma illustrates Goffman's quote:

Louisa: It's just hard because I don't know who to tell or how to..I know how, I don't know who I actually tell and if I do tell them...like I've had a few comments now, but if I do tell them, you know, what would be their reaction afterwards or will they start spreading the word...or, and it's not a thing that I'm going to be upset about people talking because now I've come to terms with it and you know, I know how to defend myself a bit more so if people do start talking, I hold my head up high and say 'Yeah I have got HIV' you know, it does happen, but I can understand the need to tell, I just don't know if I should...(aged 17yrs)

Like other participants Louisa is aware of the possible repercussions of disclosing her status; and the decision to tell another person involves assessing the risks and benefits; the possible gains from revealing on the one hand, and adverse reaction on the other. Such decisions are influenced by, and have to be placed within, the social context of each young person's life (Ragins et al. 2007; Ragins 2008). Young people have to feel sufficiently strong and self-confident to consider telling others because they have to deal with a range of reactions.

Disclosing HIV status has been associated with increased social support and increased self-esteem for both adults and young people (Emlet 2006; Michaud et al 2009; Lam et al. 2006; Serovich 2001; Sherman et al. 2000; Smith et al. 2008; Zea et al. 2005). Several studies of young people who tell others have reported higher levels of self esteem and positive health consequences (Ferris et al 2007; Sherman et al. 2000; Wiener and Battles 2006; Wiener et al. 2007b).

However, whilst the literature suggests there are positive effects of disclosure, young people may not be aware of the benefits of disclosure or of this research and report that; they are generally advised by professionals and their families not to tell. This is particularly the case with biological parents, especially HIV positive mothers (Michaud et al. 2009).

Catriona acknowledges the potential negative reactions from people:

Catriona: I don't know about telling... I mean you get the odd people out there that are just like 'Oh I don't want to know you' like 'I could catch what you've got' and stuff like that...so I don't know, I think people are too judgemental about HIV, they don't treat it like other stuff, don't judge unless you know the facts. (aged 17yrs)

Participants take decisions about disclosure believing that HIV is viewed differently from other conditions, partly because it is contagious. As highlighted in Chapter 5 the contagion element of HIV is consistent and prominent in young people's narratives. The infectivity of HIV accompanies the moral discourse around HIV and the 'judgements' of others. According to Sontag, HIV/AIDS is now the most feared disease, replacing cancer, and the 'plague is the principal metaphor by which the AIDS epidemic is understood' (1989:130), reflecting the fear of contagion. Louisa and Catriona identify the key fears and risks in telling others that influence young people's decision to disclose.

6.3. 'There are risks if you tell'

Telling others can mean revealing potentially discrediting information about oneself (Schneider and Conrad 1980,1983); it exposes hidden feelings and vulnerabilities and can strain relationships. Participants have to handle their own feelings about telling but also have to deal with their feelings about another's response to being told. Once others are told individuals have to live with the consequences of the telling (Charmaz 1997). Participants identify three main risks in telling others: firstly people may stigmatise and

reject them, secondly they may lose control over the information and people will tell others. And thirdly, some fear the criminalisation of HIV.

‘People won’t want to be near me’- The risk of rejection

Participants identify the fear of rejection as Samuel describes:

Samuel: It’s not that I don’t want to tell my friends, but it’s just to keep them where they are comfortable with me and comfortable with themselves...cos I imagine if I told them..it would be difficult for them to actually like even share a drink with me, or be around me, you know things like that, so it makes it difficult, even if they were okay, it would always be there. It’s better for them that they don’t know, cos it makes it easier for them to deal with me because if I told them some people would feel uncomfortable and they would always be trying to be very cautious with everything they do ...(aged 19yrs)

This suggests that telling someone may alter their relationship and may result in rejection; ‘normal’ social contact and interactions could be more difficult once people know. Samuel perceives that some of his friends would feel awkward around him and therefore it is easier for him not to tell, as this preserves his friendships. Like other participants, Samuel is aware that some relationships may not survive the telling, and does not want to risk being ostracised by his friends. HIV has already disrupted Samuel’s friendships and his strategy of pretence enables him to manage the disruption (Bury 1982). Samuel seeks to both protect himself and his friends. Young people with HIV have reported similar concerns regarding disclosure to friends in other studies (Bond et al 2000; Miah 2004; Melvin 2008; Lewis 2001; Wiener et al. 2006).

Neema for example, expresses concern over how disclosure may affect her social contacts:

Neema: I haven't said anything to anyone and nobody still knows, and I think if they did know they would start judging, just like not coming near me again and stuff, none would sit next to me and I'd have no friends..(aged 17yrs)

Participants' fear includes being physically avoided because they perceive that people are frightened of being infected. Ruth explains:

Ruth: I'm kind of glad that I didn't actually tell anyone when I was younger because I think it would have made it worse for me now in the sense that it might have been used against me in a way. I wouldn't have wanted to be discriminated against. I've heard the virus being discriminated, but not me directly. I felt if I told someone about HIV I thought I was going to be straightaway 'You're this you're that' that's what I was really scared of the response, I was scared of what of how I was going to cope with the rejection and in a way that kind of affected the way like with people in terms of relationships with guys. I didn't want to go into it because of all that...(aged 20yrs)

Young people live in constant fear of other people finding out and worry about being able to deal with their response (Michaud et al. 2009). Charmaz observes similar concerns amongst adults with chronic illness, where they have to deal with their own feelings about telling as well as the feelings of the person being told (1997:118). Ruth is wary of disclosing a stigmatised identity and the potential for discrimination. However she separates the discrimination of HIV from herself, and successfully distances herself from HIV. The fear of 'felt stigma' for Ruth has already altered her relationships and behaviour towards other people (Scambler and Hopkins 1986; Schneider and Conrad 1980). Ruth, like others, avoids relationships for fear of the difficulties disclosure could bring. Similar patterns of behaviour have been reported in studies with HIV positive young people in the US and Canada (Fernet et al. 2007; Wiener and Battles 2006; 2002). Participants fear

losing control of information, because it may prevent them from being able to 'pass' as uninfected in the future.

'Others will tell'- The risk of uncontrolled disclosure

As Charlotte and Elijah explain, participants recognise the risk of others disclosing their status:

Charlotte: I felt a bit pressured because I wanted to be honest with people I regarded highly, friends and boyfriend. But the one thing that stuck in my mind was something Jan (psychologist) said, she said 'Once you tell you cannot un-tell' and that made me scared. And then I thought that if my friends found out that teenage life being what it was, that if we ever had an argument they could tell people and then I wouldn't have any control over who knew and, although until they knew I would appear the same as everyone else, once they knew they would know I wasn't the same. And then I suppose some people who didn't understand the situation who would, whether intentionally or not, cause me pain. (aged 19yrs)

Elijah: I don't want to be telling no-one, I don't want to have to be explaining myself to nobody. And be telling them 'Right, you know what I've got HIV' and the next thing you know I'm the talk of Catford. The talk of Lewisham. The talk of the whole West End, nah, not init.(aged 20yrs)

Telling others means relinquishing control of who knows and may result in indiscriminate disclosure. Charlotte observes that whereas adult friendships tend to be well established, young people's friendships may be more transient and fluid. Young people may have fewer choices when thinking about disclosure than adults, as their resources may be less well formed (Bury 1982). Disclosing can potentially damage and hurt young people, because they fear that the information will not be contained or their confidentiality respected.

'I might go to prison' – The risk of criminalisation

Several young men identified the risk of criminalisation and HIV if they were to have sex without disclosing their status, as Elijah and Mark explain:

Elijah: No way, no way, like I said, tell anyone and I would find myself on the ITN news, ITV news. Do you want to make up a lie and say I agreed to her and I had sex with her, I haven't touched her. I told her I had HIV... there going to believe her....So you can imagine the whole HIV thing, like whoa, whoa you're going to prison mate. You're a dead man. You might as well kill yourself. That's just suicide like, serious.

I don't go into relationships, I do the best friend bit, I've come close to it innit but I just can't do it, it's too much. (aged 20yrs)

Mark: I am thinking about the consequences if I do tell her, I might go to prison like, but I think if I go to prison, I go to prison... I am scared I will infect someone and my worst fear is that I will go to prison over it....(aged 18yrs)

The link young men make with disclosure and possible criminalisation of HIV may reflect the increasing number of court cases of 'wilful transmission' of HIV being reported in the media (NAM.2009). Elijah extends this link to the issue of consent and disclosure in sexual relationships, highlighting his fear that he may not be believed. Young men feel particularly vulnerable in sexual relationships regarding their legal position and this appears to influence their disclosure decisions as well as decisions about delaying or avoiding relationships. Delaying or avoiding sexual relationships has been reported in other studies (Ferner et al. 2007; Wiener et al. 2007a).

The risks of disclosure may outweigh any advantages. The next section goes on to consider why some young people decide not to tell.

6.4. 'I don't want anyone to know' – Those who do not tell

Of the twenty eight participants, fifteen (54%) – six young men and nine young women report that they had not disclosed their HIV status to anyone outside the family. When adjusted for the sample, 55% of young men report not telling and 53% of young women.

Why participants decide not to tell varies, as Mark reflects:

Mark: my worst fear is to be, for people to know about my status and to look at me differently, that's what I'm saying, I don't want anyone to know, so I'm not telling anyone.....I personally hate even thinking about it to tell you the truth, it's caused me so much stress...(aged 18yrs)

For some young people disclosure merely acts as a reminder of their status; not telling helps some forget about having HIV. Participants are able to put HIV to one side and do not see HIV as part of a master status, which enables them to continue to function as uninfected and unaffected by their diagnosis. However the stance of not telling may change with time, and participants observe how it can get harder as they get older. As Paul explains:

Paul: I think if I was going to tell my best friends, I think I should have told them when I was younger, cos then they could have grown with me, but it's a lot harder when they are 20's and 21.... I would like to tell my friends, yeah I would, but I don't let it get in the way of me you know (silence) it's like I think like secrets are boring and I think I will have to tell them sometime (silence) I will probably be sick when I tell them, like on my death bed (laughs) it's not the best time to tell them, but eh (laughs) I don't know I think, I'm not sure if I knew what I know now then, I would have done it already, I would be able to tell that story, that page in that book hasn't come yet, and I really hope, I hope, I hope, I can only hope that they will be fine by it and just, I think more and more they will be more upset that I

didn't trust them, I do trust them, but it's like all that sympathy shit, I just want to be the same old Paul..(aged 24yrs)

Participants live with the assumption that other people do not know they have a stigmatised identity. For Paul, growing up as someone that he assumes is thought of as uninfected raises uncomfortable issues of betrayal and trust. Having previously 'passed' as normal (Goffman 1963) the decision to tell someone is consequently more complicated. Paul can only consider telling as a last resort, because he views telling as changing relationships. He also has to be able to live with the telling (Charmaz 1997). Considering telling involves disclosing a different view of self to the world and risks changing how others view him.

Other participants, such as Matthew, recall situations where they wanted to tell but felt unable to:

Matthew: The person I should have told was the person I almost had sex with but I didn't 'cos I was far too nervous. ..we didn't really have sex, she was too pissed really and I couldn't do it, I got the condom on but then, I just thought I have got to get out of there. I remember I thought 'I'm just going to walk home' it was about four o'clock, I remember walking home it was the longest walk in my life...I really felt that I could have given her the disease and all the problems that I go through. You know it's not fair to give that to someone. She was really nice as well, but she was a bit promiscuous. I felt ashamed of myself cos I should have told and I was surprised by that because I thought, you know, when the time came to tell someone when I wanted to have sex I thought I'd have the guts to say it and I was surprised I didn't.

And maybe that's from my parents being very secretive, hiding it, or just the nature of the disease, you've got to be secretive, and hide it all the time.. I didn't tell her cos I didn't know how she was going to react, I think I was really nervous 'cos I thought if I told her I wouldn't be able to have sex and, I mean saying that

now, that's an awful thing to say. You know, sex or get HIV, you know. And you can have sex and you can't get it if you wear a condom and have sex and don't get it, you know. And saying that sounds really stupid but that's what I was thinking at that time..(aged 18yrs)

Most participants have not told anyone their status and their only experience of disclosure is when they were told their own HIV status. Matthew was shocked and shamed by his behaviour, because he anticipated he would disclose his status to a sexual partner. When faced with the reality of disclosure the fear of the consequences were too great for Matthew. Later on in the interview Matthew spoke about how he had subsequently contacted a sexual helpline and, later, hand-delivered a letter to the young woman advising her to get checked up at a sexual health clinic, without specifically mentioning HIV.

Most young people carefully ensure their HIV status is hidden; indeed, they report being advised to keep it secret. This advice was given to young people at the time of disclosure and had not been followed up with subsequent conversations to discuss whether this situation had altered or circumstances changed. Although the advice may have been relevant at the time of diagnosis, this is not re-visited as young people move into adulthood; therefore when they are faced with a situation where there is an expectation or they feel they should tell, they find it particularly difficult. Most, like Matthew have not been prepared or supported in acquiring the skills to disclose their status to a partner.

Matthew found having to make the decision about disclosure stressful because of the circumstances; this experience disrupted his life. Biographical disruption may also be experienced by those who decide to tell. Although more than half of participants report not telling, nearly half reported telling and their accounts are considered next.

6.5. Those who tell

The decision to reveal a stigmatised identity is motivated by a range of factors and circumstances. Although Michaud and colleagues' study (2009) of twenty-nine young people found 21 (72%) of young people had told someone outside the family, other studies found that the majority of young people with perinatally acquired HIV chose not to share their status with others (Battles and Weiner 2002; Sherman et al. 2000; Wiener and Battles 2006). In this study, thirteen (46%) young people report disclosing their status to someone outside the family and seven (25%) report telling a good friend. Young people report finding disclosing their status to another person emotionally distressing and Michaud and colleagues' study (2009) found that participants became upset when recalling the experience. In my study most young people did not get upset when talking about disclosing to other people but, did report it as an emotionally distressing experience.

The reasons young people tell are complex and may relate to the centrality of HIV in their everyday lives, or how openly it is managed at home. Where HIV infection occupies a major and active part of an individual's life the need to tell may be greater. When HIV is separated from their everyday life there may be less need to tell and therefore a greater likelihood of keeping it secret. On the other hand, if HIV is openly discussed and acknowledged at home it may be easier for young people to consider telling others. Moreover when a parent has already told others a young person may be more likely to consider disclosing to others.

Young people spoke about disclosure decisions at length suggesting they were significant events. For some, the decision is reached only after considerable thought and assessment, whilst for others, it may be opportunistic. Three major variables influence the decision to tell; first the need to share the secret, second, as a response to an event or secret shared, and third to protect others from the risk of infection, primarily in a sexual relationship. Whilst most tell hoping for support and potential benefit, this is not always the case. Whatever the motive for disclosure, it can also be seen as giving voice to their HIV;

being recognised and seeking acceptance and validation as someone of worth (Creed 2003). Young people may want their friends or family to know their status because they want them to know all of them, to reveal the part of their identity that includes HIV. The biographical disruption an HIV diagnosis brings is amplified because of the stigma attached to it and this results in the need for secrecy. Breaking the secret allows young people to find acceptance of their new identity of which HIV is a part. Disclosure can be a disruptive experience as young people reveal a new and stigmatised identity to people that have known them and assumed they are not HIV positive.

'It's just too much for me' - The need to share the secret

Some young people spoke about their need to have someone else know. Louisa recalls an event when she was fourteen:

Louisa: I didn't tell anyone until I fully understood what it was about ...and I'd written the first verse...the first person I told was my best friend,.. she reacted in the same way I reacted, she just started crying, so it was a bit difficult. She just cried and cried and cried. 'You're dying', I said 'I'm not dying'. I had to sit her down and say it to her the same way...I had it said to me..I said basically it was like, I was my mum talking to me a year ago sort of thing, and basically saying to her 'We're all going to die sometime' and all that stuff.

I felt I needed to tell her because I don't know, I see it as someone to ..besides my mum and dad I needed someone else to talk to. Someone who's my age and who understands this, and at the time obviously I'm going through the mad telling thing, the whole guys and sex and all that stuff. And I thought to myself 'Well, wow, what am I going to do?' So I thought 'you tell her' and she was really supportive actually. She came to every hospital appointment with me up until now so I felt that now, you know I'm growing up I should do this by myself...so she's

been alright since I told her and she's kept it confidential as far as I know. (aged 17yrs)

Most young people who tell, tell someone of the same age, others decide to tell an adult. Within the extended family, twelve (43%) participants report that aunts, uncles and grandparents were told of, or knew their status. Sixteen (57%) report that to their knowledge, no extended family members had been told but this does not necessarily mean that these family members are unaware.

Denisha comes from Uganda where both her parents had died from HIV and she was adopted by her father's wife, (her mother was his mistress). Denisha recalls telling her aunt:

Denisha: My mum (adopted) was like 'If everyone knows then there's going to be a stigma and people are going to start treating you different' and I was like, I wanted to tell my auntie when I knew innit and she's one of my closest aunties, I talk to her about everything. And my mum was like, 'No, no, no' till the age when I was like 15, I think and then like I said to the Doctor 'I want to tell someone else 'cos it's just too much for me innit' and they were all like, my aunty cares so much for me, and at that time I was getting very ill and stuff and I was in hospital for like half of year ten and year eleven, so that affected my GCSEs and stuff like that. And so I eventually told my auntie innit.....

It was alright and everything, not as bad as my mum thought it would be. She came to the hospital innit and said like, you know how come she's always ill? She's come to visit me innit, and she asked 'What medicines she's taking? Why is she on this?' She keep asking questions innit and they can't be saying, you don't know innit, and eventually I told her. She was like 'Oh why you not tell me sooner?' I was like, 'But I wanted to tell you when I was 13, but my mum told me I

couldn't'. So she's glad she knows and I am.....it makes me feel better..(aged 18yrs)

Denisha finds keeping HIV secret difficult and she wants to tell someone else. A young person may feel disempowered from telling because of the assumptions that adults expect HIV to be concealed; consequently participants rarely challenge their parent's wishes. However, sometimes the need to tell becomes greater than their anticipated fear of the consequences. Telling others brings benefits for Denisha, making her feel better and able to be more open with her aunt. Denisha's decision needs to be placed in context, her life had been dominated by serious illness, loss and bereavement, thus her need to tell her aunt may emanate from other factors than her HIV.

Being able to tell someone who you know cares for you may not only offer relief in being able to share part of an identity kept secret up until now, but may also offer support, acceptance and validation (Charmaz 1997; Lyon and D'Angelo 2006; Smith et al. 2008). This could be seen in part as young people's need for affirmation and acceptance of their stigmatised identity (Swann 1987). Telling another allows for the possibility of finding a stable and more positive view of self reflected in an acceptance by others, even if that other is just one other person (Michaud et al. 2009; Swann 1983,1987).

Some young people wait for an opportunity to tell others and this is considered next.

Sharing a secret and an opportunity to tell

Alica recalls:

Alica: My friend had gotten Chlamydia or something and she was talking to me.. 'Oh I've got to ring everyone and tell them I've got it and I don't want to' and it's that kind of conversation. And she wasn't making out like it was the end of the world 'cos she's not like that, but she just...I could so...I could understand for once how she felt and I was just like, I turned to her and I said 'you're going to really hate me, but I've got something I have to tell you. I've got a really big secret!'

(laughs) and she was like, what is it? And I went 'It's not a good secret, it's a bad secret' and she went 'You're not going to die are you? I said 'Yeah, I am (laughs) and I just sensed that look, she goes 'What?' I said 'Well, not right away, but I could do' (laughs) and I tried to make it into a bit of a joke...(aged 19yrs)

Alica seizes her opportunity to share her secret when her friend discloses a sexually transmitted infection. Although telling her friend is prompted by a momentary shared identification and understanding, this quickly moves on to become an opportunity to minimise her friend's distress by displaying her own, which is far worse.

Some participants, including Sarah, spoke about telling others in response to a serious event or situation:

Sarah: I have only told one friend, that's one of my school friends, but I wasn't even going to tell her. I only told her because she was suicidal, her, her boyfriend had dumped her (laughs), so I told her, look you've got your whole life ahead of you, you can't be committing suicide over a boyfriend, and then told her, look there are people who basically you know, value, wish they could have a life, me, I'm not saying that I don't have a life, HIV just makes you more prone to things doesn't it, so I told her basically that uum, I need to tell you something, and that I just told her that I was diagnosed with HIV when I was younger and stuff and you know, and that uum, she stopped feeling sorry for herself (laughed) 'cos you know things could be worse, kind of thing and she was ok with it, she, I was really surprised she took it really well, she said 'No, I don't see you different, you're still the same, you're still my friend'.

It felt really good, it's not even an issue and stuff, and she's a very good friend, she has never told anyone and she's known about it, I should say five years now and she's never told anyone.(aged 23yrs)

HIV challenges young peoples' normal assumptions of the invincibility of life. Living with a limited life expectancy is hard for them and Sarah envies her friend's situation. Her reasons for telling are mixed, in part prompted by wanting to share her diagnosis, but also by the unfairness and sadness of her situation. As well as receiving the anticipated support, Sarah also receives validation and affirmation from her friend rather than rejection. Thus friendships can survive the disclosure of HIV status. Young people are aware of the risks of transmission of HIV and one reason they decide to tell others is to protect them from the infection. We turn to this next.

'I don't want to infect anyone' - Telling to protect others

The beginning of a sexual relationship marks one of the first times participants recall considering disclosure. Of the nineteen (68%) young people that report having sex, eight (42%) reported telling a sexual partner their HIV status. Many participants acknowledge an ethical dimension to the decisions they make in relation to protecting others in sexual relationships. As Charlotte reflects:

Charlotte: Being in a relationship, is the only time you really think about telling, for me it was at a point where I was secure enough in the relationship that I'd be happy sharing that sort of information with someone, but it wasn't too long, but I don't feel bad about keeping it secret because it's about balancing my needs against his I suppose.

I suppose the self preservation part of me kicked in. I decided that I would not tell him as soon as I could have done because I needed that security. I needed confirmation that he wouldn't run off at the first sign of danger because of the very same preservation reasons. That his need, well my need to protect him, and his right I suppose, to have all the information me then, yes, he did need to know. I suppose, to have all the information persuaded me then, yes, he did need to know.

And the closeness, I have told him, I suppose we could be considered best friends. Although we tell everything to each other and how he knows all my history, I know all his. That's more of a friendship because we're in a relationship, and that got me to be honest, more honest than if I would have been if it had just been a friendship. I didn't want anything to happen to him and for it to be my fault, I couldn't do that to him.(aged 19yrs)

Young people then have to balance the need to protect a partner from the possible risk of infection against the need to preserve their own secret and a non-stigmatised identity. Trust needs to be established before they can consider telling therefore disclosure to a sexual partner appears to be about balancing and assessing risk; this includes assessing sexual risk and exposure to HIV for their partner as well as the risk of disclosing their own HIV status to another.

Participants learn from experience about telling sexual partners. Sarah reflects:

Sarah: I was with him for some time and stuff, because in relationships you have to build that trust and stuff and I know some people don't, but you do learn from experiences 'cos you're still growing up and you don't really know what to do when it comes to relationships, so you know, but I have learnt that it's good to tell the person before you sleep with them even though you're going to use a condom.. 'Cos, my first boyfriend I didn't tell him, till after I had slept with him after a while and stuff and then eventually I told him 'cos I really liked him and cared for him and stuff, but it's just a matter of how. I suppose that was the main thing and how and stuff and that didn't work out and I could understand why.

JD: What happened?

Sarah: Uum, he was hurt like anyone would be, you know that I didn't tell him 'cos that had put him in a very awful position.....like he could have got it, ..to be honest and stuff so he was hurt, but when I eventually did tell him and stuff, uum we are still friends and stuff, but he was hurt like anyone would be and I could honestly understand. He left and I don't really blame him. (aged 23yrs)

Disclosure decisions change over time and young people learn from their experiences as they are in transition to adulthood. Most participants are selective in deciding which partners to tell and few told every partner.

Trust was the most important characteristic identified as well as knowing the person for some time. Most young people did not report telling those with whom they had 'casual sex' which most defined as either 'one night stands' or a week or so. However, Alica was unusual in that she recalled telling each boyfriend her status and she explains why:

Alica: Well I've always told them, boyfriends that I've you know..(laughs), not like boyfriends I had when I was five (laughs) yeah I've always told them

JD: Has that been a conscious decision?

Alica: Yeah, I've always, I don't know why, I think it's, I don't want to keep anything....it's a big thing, I know it's a big thing, but I wouldn't want to keep it from anyone in that way, you know. If I know they are at risk by sleeping with me then obviously I have to tell them. It's my responsibility and...Surprisingly they've all been fine..(aged 19yrs)

Alica feels a responsibility to tell others in order to protect them. She views HIV as too 'big' not to tell sexual partners but her openness may be influenced by her complex family circumstances. Alica's mother has experienced recurrent mental health problems and has

disclosed her status indiscriminately within the community. Following her father's departure from the family home with her younger sister who is also HIV positive, Alica became a full time carer for her mother. The knowledge of her mother's status within the community may well have affected how Alica has decided to manage disclosing her own status. If she did not tell, she risked people finding out from other sources.

Other young people identified how wanting to have unprotected sex, or a partner wanting to have unprotected sex, can act as an additional prompt to disclose. Ruth is twenty, and currently in a relationship of four months. She recalls what prompted her to tell:

Ruth: It was just the fact that I'd been with people before and I thought that I have just, I have to learn to get over this bridge, unless, because if I never get over that bridge it's going to make it harder as time goes on. So I thought that was one thing. And the second I thought he was the right person to tell just because he was more responsible. He was more mature and he respected me as well. So I thought he was definitely the right person to tell. But then it's made me think as well if I don't think that about any other guys then I shouldn't be with them. So maybe in one aspect it's made me think 'Yeah, I've got to make a decision'.

I've been going out with him for about 4 months, and I didn't want it to go on too long, because I mean, after like a couple of months it's quite, it's hard to tell someone even after all that stuff you've been through, and because in case if I go too long and in case an accident happens, condoms breaking and stuff. I'd rather tell him before it happened so that instead of saying at the time because I would have to say it straight away, and I know that would be even harder. And I didn't want to do it too early because obviously the person has got to know you and the whole situation and another aspect was he wanted to have unprotected sex. So, that's when I said I've got to let him know straight away... I thought it was maybe the right time to say it, and I got to know him as well so..(aged 20yrs)

Telling sexual partners, and finding the right time to tell can be complex, so a partner's request for unprotected sex may act as a prompt to either tell or leave. Participants view those who engage in protected sex as responsible and respectful. Ruth's reasons for telling are two-fold, firstly the fear of infecting but, secondly her partner wants to have unprotected sex. Samuel also identified unprotected sex as an issue that influenced his decision to tell his girlfriend:

Samuel: When the thing was getting like, you know, because there's that point like when your relationships and feelings and when you want to experience things yeah so that's when I...I just decided I wanted to tell her. You see the problem is before, before she pushed me into doing it without the condom, you see, and I refused, then that was because it was easier for me to explain than keep doing it without a condom, that's why I refused then, you know. And then she was like, 'Oh that's why, it makes sense now' you know, that's it. I was thinking, I was just thinking as in it's risky for her. (aged 19yrs)

Negotiating condom use can be difficult because young people are aware of the need to protect others particularly if they have not disclosed their status. Whilst on the one hand Samuel appears to blame his girlfriend for pressurising him into unprotected sex, he is aware of his responsibility and wants to protect her and himself. Sexual relationships can amplify the dilemmas young people with HIV face about disclosure. Participants reported a range of disclosure experiences some of which were not as positive as they hoped and these experiences are discussed next.

6.6. 'I thought I was going to be lynched' - Bad experiences of telling

The bad experiences participants report following telling usually relate to loss of control over information in the disclosure process. Alica describes her boyfriend's behaviour after she had told him:

Alica: I actually found out something which really pissed me off, which was he went and told his best friend about me. And the way I see it, nobody should know or I should only tell who I want to know, if you get what I mean. Like it's not for my friend or my boyfriend to go round telling people about me. It's for me, it's mine to say to whoever.

When I asked him about it, he told me that 'She probably won't even remember we were both really drunk', and I went 'I don't care' It made me feel very, like alienated and every time I went round there I felt like everyone was watching me and that she had told everyone and that, and that I was taking her best friend away and that, you know, I'm this diseased harlot, you know it did put a strain on the relationship as I felt he had overstepped the mark.. (aged 19yrs)

Once young people make the decision to tell they expect recipients to respect their confidentiality and understand the risk they have taken in telling them. However once the secret is shared who is subsequently told is out of the young person's control. Alica fears the moral judgement of others who she did not choose to tell. She fears people may judge her and view her as sexually promiscuous and infectious. This is reflected in her use of the phrase 'diseased harlot'.

Wiener and Battles (2006) report that a feared consequence of disclosure that young people identify is the change it can bring to relationships; disclosure may generate negative emotional reaction that adds strain and damage to a relationship that was established under the guise of normality or non-stigmatised identity. Those told may feel betrayed, shocked, foolish, uncomfortable, or even threatened by the revelation, or upset at being deceived, feeling their friend did not trust them enough to tell them. Their perceived dishonesty may affect the relationship. Having told, young people lose control over how the recipient interprets the information.

Some participants recall particularly bad experiences of disclosure at school:

Denisha: It was alright apart from one time, yeah, some shit must have..I don't know how she found out, but she just started spreading it round my class, but it didn't go too far cos the girls she told were my best friends and they go to me 'Oh, Jo said something about you and I want to know if it's true, we think it's shit 'cos if you did have it you would have told us already innit', and they said it and I go 'What are you saying this for innit' had to deny it because at the end of the day like....it was in secondary school, they weren't, I don't know if they were my close friends or not.

So I was just like 'No, innit' and she must have said it very loud in class, yeah, and cos my two other girls were like, 'Oh shut up man, you're chanting shit, you're chanting shit'. She allowed it, she didn't say nothing innit, because I did tell her, I did tell her thinking she'd keep her mouth shut and then she didn't so I had to say, 'Do you know what, she's lying about that'. I just think, do you know what, I'm not telling anyone, since then, yeah I just did what my mum said, you need to watch who you tell. (aged 18yrs)

The knowledge of the collective experience of discrimination and prejudice plays a part in decisions to tell others. Whilst Denisha was able to convince her school friends she did not have HIV, Amy had a different experience, she recalls revealing immediately after she found out her status:

Amy: I was pretty mad at first, I went down and told one of my friends and you know what I'm saying, well it was a close friend, but she didn't believe me and went round telling everyone that I was lying about having HIV. Then they actually believed it, cos everyone then knew. Everyone kept coming up (at school) to me and asking me 'Have you really got HIV, is it true, is it true?' I was like 'Leave me

alone, go away' and they just kept doing it so I went to the main office and said 'Look', they all knew about it as well and how many years and all that. They knew I had it, when I didn't know I had it.

JD: How did that make you feel?

Amy: Like the last person in the world to know (laughs) and then on from there I said 'I can't be at school where everyone knows about me' There was eight of us that used to hang around together, all together, and they all knew because of obviously this one person. And then she sat there with her arms crossed on the table going 'Well I don't believe her. I just think she is an attention seeker'. I said 'Look Lucy I didn't tell you for you to go round telling everyone, I told you as a personal person because I don't know what else to do' and she was like 'yeah well I reckon you're just an attention seeker' and I said 'Oh whatever you want to say' and I walked out of school and never went back. That's why I never got any GCSEs or nothing. (aged 17yrs)

Unintended disclosure can cause chaos in young peoples' lives and managing unintended disclosure is difficult. When a friend tells others and betrays a confidence, young people report that they find it hard to rebuild relationships. Amy gains control of the disclosure by removing herself from the situation which results in her losing her only network of friends and support and creates further isolation for her. Friends however, are not the only people to break confidence; family members can too. Joanna is 18 and one of three adopted siblings, following her diagnosis her younger sister and brother were sent to boarding school. Joanna told her sister her status:

Joanna: My mum was absolutely furious with my sister. To start with she was annoyed with me for telling her but then I kind of explained that I needed someone my age. A year after that, we told my brother and we thought he might be a bit like

my sister, but he was really decent and he like would go up to my mum and ask what it meant and was I okay and stuff.

Whereas my sister was going round her school saying that she was the only one looking after me and would never go to my mum and ask what it meant or whether I was ok or she wouldn't ask me. She just like used it for her own benefit. So I've told her that if she does it again, you know, she won't be forgiven next time, 'cos she would keep ringing up family and it was like awful because I'd refuse to go (to the school) and mum didn't really want to go either 'cos you know it was like one of the most secrets we had in the family, and she had kind of betrayed it, and so it kind of split the family up a bit. (aged 18yrs)

This extract illustrates that bringing HIV into the open in a family can create strains on relationships and alter the dynamic. Joanna viewed her sister as a safe person to share her secret and her sister's telling was seen as betraying the family secret. Joanna's account clearly defines her sister as the 'bad sister' in telling others to gain notoriety and attention, whereas her brother was seen as the good child, in that he kept the family secret safe and showed concern and interest. Uninfected siblings may feel overshadowed by the attention received by their infected sibling.

Mellins and Ehrhardt (1994) observe how uninfected siblings reported feelings of anger and jealousy. Whereas Joanna told her sister intentionally, Alica recalls her experience when a boyfriend unintentionally found out from her mother:

Alica: I had this boyfriend, this is when I was 13/14 and I went to secondary school, and he was like a year older than me and he had a friend and they used to come round and then his friend remembered my mum used to go out with like his dad's friend and my mum had told him, and then he told my boyfriend. 'Oh that girl's got HIV' and basically there was like this one time in town, I was so mortified. He basically followed me and my friends round shouting it out in the high street.

And obviously my friends had no clue what he was talking about. I was basically turning round and shouting at him telling him to stay away from me and shut up right now, all that. And they were saying 'what's all that about'. And 'he's just an idiot, what do you expect'. He was saying things like 'I hope you die of cancer' which to me was just a bit, cos I would like (laughs) wouldn't it be AIDS if you were going to say something like that (laughs).

I was a bit scared actually cos I thought what if like, my friends had gone on his side or, you know, said 'Oh he's lying' this, that and the other. Cos I hadn't told them, but luckily they just brushed it off and thought he was a bit of a loser. I felt really scared cos, I felt like, well, I thought I was going to be lynched. Even though it was only two people, I thought if anyone else heard it and decided to believe it people could just start on me and you know they could remember me.. 'Oh that's the girl that..she's got HIV blah blah, I mean I felt really scared. (aged 19yrs)

Alica's experience illustrates the frightening nature of losing control over disclosure. Young people have no control over how others may react to this news; consequently they have to find a way to regain control of the information about their HIV status.

6.7. 'I'm giving part of myself away' – How participants tell others

Telling others makes young people vulnerable and exposed because they are revealing a secret and potentially discrediting part of their identity (Charmaz 1997). There are different ways of telling and young people tell in different ways.

Alica and Ruth recall how they told their boyfriends:

Alica: I waited until we got to my house and I sat in the car and I said 'You're going to really hate me but there's something I've got to tell you' and he was like 'OK', and every time I always get, I always get watery eyes and I feel like I'm giving part

of myself away and it's cos it's not secret anymore. And I just kind of told him I was HIV positive and he went 'Is that it?' and I went 'What?' and he said 'Seriously like I thought you was going to say you were pregnant or something' (laughs) 'Thank you very much', but it made me feel better. (aged 19yrs)

Ruth: I told him a week Friday, yeah, that was the first time I've ever disclosed it to anyone like, so it was quite nerve racking, that was quite nerve wracking. It was quite funny actually because I told him over the phone (laughs) I wouldn't recommend it, but I did it over the phone. I just said that I needed to talk to him over the phone and he was very nervous 'What is it?' because I said it was really important but he really wanted to see me so, he called me that day and then I told him, like that day. His reaction was quite funny cos he goes, when I first explained to him, he does 'Oh is that it?' and then 'I thought you'd cheated on me and I was about to pack my things'. And I was laughing quite hysterically because I was quite surprised at his reaction. He was like, I mean, 'cos, because I've never had unprotected sex and I've always been like, the way I hold myself, I wouldn't want to pass anything on. I'm quite responsible, so he respected that. (aged 20yrs)

Telling other people can be difficult and upsetting for young people, because they risk being rejected. Once the information is shared it cannot be retracted and they have to live with the consequences of whether or not they made the right judgement. Young people run the risk of losing both an important relationship as well as their 'unspoilt' and creditable identity; they also fear being thought of as irresponsible or having put their partner at risk. Alongside telling, they have to re-assure and educate their partners at the same time, offering an explanation as to why they exposed them to risk. They also have to deal with their own feelings and responses of others. Whilst the responses Ruth and Alica received were ultimately supportive, the stigma of HIV was re-enforced because their partners' immediate fears were about pregnancy or infidelity. These are seen as 'normal' concerns. Ruth reflects on her boyfriend's reaction:

Ruth: When I told him he was shocked, because he never imagined it for me. He said I'd never think that I'm someone like he would think would have HIV. He was really grateful that I told him and he asked me lots of questions, like he goes 'So what' and 'Dying?' that was one thing he said and I said 'No' and he was like 'So what's changed since' cos he knew that people die from it and he was asking how it leads onto AIDS. Can I have children? A lot of questions he was asking me, I thought a lot of people knew there was medication for it, but people don't actually know that. They don't know how it works and stuff. So he asked me a lot about that, I mean his reaction was very good in terms of he was very supportive and just wanted to know more and I think I am quite lucky in some ways because Ihe has never said.... I've been around a lot of people and friends, ex boyfriends who've said a lot of negative stuff towards HIV.

JD: Like what

Ruth: Like what you get HIV, you're going to die, you know really negative reactions like that. They'd say stuff like ..they'd think it was an automatic death sentence, or that people with HIV are like this they have an image in their heads that someone with HIV is an ugly horrible monster that sits in the corner.. (aged 20yrs)

Ruth has to work hard to convince her partner she is well, can have children and therefore has a future. Managing others' reactions and feelings is difficult for young people; Ruth needs to be able to answer his concerns and get him to accept the situation. Her description of the 'ugly monster', reflects how she fears she is seen. It can be hard work for participants to convince partners they are worth staying with and Ruth hopes her relationship will survive disclosure. Some tell anticipating rejection such as Amy:

Amy: I told my boyfriend, I had just found out, I told him crying (laughs) but he was alright about it, he just said to me 'Oh go away, you've never got HIV' and I was going 'I didn't know how to tell you but you don't have to come near me if you don't want to' and he was like 'No don't be silly'. (aged 17yrs)

Some participants found including the story of how they became infected made the stressful and difficult job of telling a partner easier. Their accounts are considered next.

6.8. 'It's not my fault – so it's easier to tell' – Being born with HIV makes telling easier

Participants identify the significance of how they acquired their infection when they disclose their status to others, particularly sexual partners. Young people perceive that as their HIV infection was not their fault then others are less likely to blame them and more likely to accept them. As Sarah reflects:

Sarah: I told him like I contracted it when I was young and he was fine with it and stuff and he was happy that I had told him, and he didn't see me as different in anyway and he was really happy that I had told him, but the thing is, uumm, it is people's perceptions, people are....very, he was accepting, he was accepting to me because it wasn't my fault of how I got it, but if I had told him that it was through unprotected sex, that's how I contracted it, he said he wouldn't have got with me, and I think you really have to look at the situation because if a girl doesn't know a guy has HIV, it's not her fault that she got it too, but she did have sex and stuff, so you know people do have to look at, look at situations and stuff before judging. (aged 23yrs)

Sarah is critical of those who make judgements about how someone contracts HIV, yet is keenly aware that her boyfriend accepts her because of her innocence. Despite the

possible consequences of disclosing maternal infection, Sarah explains the route of her infection; she wants her boyfriend to know that she is not responsible for her HIV.

Adults viewed as responsible for their stigmatising condition are more likely to be disliked, treated negatively and rejected than individuals whose stigma is perceived to be beyond their control (Crocker et al. 1998; Weiner, Perry and Magnusson 1988). Sarah's account distances her from blame or responsibility and also engenders sympathy which may help elicit acceptance by others. Most young people differentiate between themselves and those who became infected through other routes and as discussed in chapter 5, some participants identify perinatal infection as morally more acceptable than those infected via sex or drugs (Herek 2002). As Alica reflects:

Alica: I say I have always had it, I was born with it, it's not something I..and then I think that was one of the things that swayed my current boyfriend. The fact that it couldn't be helped, with me, It's not something like I went out, got drunk and had unprotected sex with someone and caught it, like it's not my fault, it's cos I was born with it. And I think that's where they are sympathetic and they're more understanding.

JD: Do you think that's made a difference

Alica: Yeah, but it's silly though because all those people like that do get it kind of just from a one night stand. It's not, you know, to me that's like really upsetting. Because they have made just like one mistake and they've got to now to deal with like disease or whatever. Whereas I've had my whole life to grow up with it and I know I'll always be with it. But for someone who just...didn't think to me....it's different. (aged 19yrs)

In summary telling others affects many aspects of young people's lives and permanently changes relationships. Deciding to tell disrupts young peoples' biography as they share a part of themselves that has been kept hidden. The effects and consequences of disclosure are considered in the final section.

6.9. Effects and consequences of telling others

Although most participants report that telling brings some relief from the stress associated with hiding stigma and concealing their HIV status (Meyer 2003; Smith et al. 2008), it can emphasise difference. As Amy reflects:

Amy: ..my friends like they totally understand everything and I feel fine, sometimes I sit there and think to myself like when they're around me and they're laughing and joking and we're all having a laugh. I sit there and I think that I hate being me. Why does it have to be me, but that's how it is, like. This world's horrible and I don't want to be me (laughs). (aged 18yrs)

Telling may lessen the stress of secrecy and bring greater support, but Amy still feels different; she does not want to be the person she is or living the life she has been given. For Amy, disclosure has reinforced the stigma of HIV and despite acceptance from her friends, she still feels alone. Telling other people can re-enforce how different HIV makes you from everyone else, whilst once having been able to 'pass', young people's identity is now 'spoilt' and 'discredited'.

'Letting someone into my world'

Some participants keep HIV separated in 'different worlds' and telling others can bring these two worlds together. As Paul explains:

Paul: I just see I have two worlds, one where I can be who I am and everything, and there is another world where people see me as they think I am, but they don't

see my other world. At present I am in my other world on my own, as no-one knows I am infected, it's just me and the virus, we have grown up together.
(aged 24yrs)

For Paul, creating separate worlds and two separate identities enables his secrecy to be maintained. It is usually in close relationships that young people consider telling others a situation which represents both a threat and an opportunity. The threat is being found out, and the opportunity is to bring the two worlds together and find acceptance and validation. Telling another person can establish a bridge between young people's two worlds. Joshua reflects:

Joshua: I had one serious relationship I would say- it was probably the longest relationship I've ever had actually and she was the only one I ever talked about my status, but it didn't work out and she left so...I decided to tell her, well I guess I wanted to take it somewhere further. I don't know, 'cos it would have been nice to actually have a girlfriend that you could tell, but I can't see myself doing it again. See if I only took that one chance, let someone into my other world, which was so hard, but if I felt serious about her, which I did, only way was to tell her before anything goes any further, I don't think I'll do it again. (aged 22yrs)

Opening up the world where Joshua kept the part of his life that contains HIV is difficult and did not work out the way he had hoped. Participants' fears about the risks of telling may be well founded for many because of previous difficult experiences which resulted in rejection. These experiences influence how participants view relationships and contribute to their feelings of isolation. Paul reflects on relationships:

Paul: Like you know, the worst thing someone can say to me is that 'Oh, you told me and I am still here with you, you know how good I am' you know, how good that is, straight away you're thinking, you know what, don't you think you

are better than me, because I have let you into my second world and you think you can haveor understand, but you can't because if you could you wouldn't be saying such things.... I would never say to someone who has their arm amputated, you know how lucky you are to be with me or how lucky you are as I have to walk down the street with you with your amputated arm and everyone stares at me...(aged 24yrs)

Paul is angry and fears that having HIV has lessened his value as a person and partner. Young people take risks when they decide to disclose their status to others. Paul has kept his 'second world' apart for many years only letting one person in, his risk has created more problems. Paul has kept his HIV identity apart. Underlying his anger is a fear of rejection and an understanding of the reality of the stigma of HIV. One of the main effects participants identify of telling other people is greater support and care and this is considered next.

'I feel so much better' – Gaining social support

Disclosing an HIV status can bring benefits for participants and most of those that have told others report feeling better. As Tess and Alica reflect:

Tess: I can talk to my friends now and I know that they know, and I know that like it's just in the open so then like even if we're talking about something completely different or something it's just like the fact that I know that they know and they don't really care. You find out who your friends really are, and that they like you for just being you which makes me feel better. (aged 15yrs)

Alica: I do feel so much better having told, yeah 'cos there's someone I can just say, 'Oh I'm not feeling great' or 'Oh I've got to go up to London' so she's like 'OK give me a text' and she's always like 'If you ever need anything, you know don't hesitate to contact us' and she's even said to me 'I might come up with you one

time' I say you don't want to come unless you need to (laughs). It made me feel like, just like finally after all these years I've got someone who I can talk to. I told her about it, I can talk to her about it and she actually wants to know what I go through. And you know she's very kind and understanding and it's that friendship at the end of the day. (aged 19yrs)

Both participants report that their friendships have survived disclosure. Their friend's acceptance validates them which in turn makes them feel 'better' and affirmed. Fears about rejection and judgements are clear in their narratives. Similar findings have been observed in studies about adults with HIV where increased social support is reported after disclosure (Emlet 2006; Serovich 2001; Smith et al. 2008). Increased support has also been reported in studies with young people (Kam et al. 2006; Michaud et al. 2009), and Wiener and Lyon observe:

Adolescents who decide to tell other family members, friends, and romantic partners were more likely to receive social support and have a good social self-concept, fewer problem behaviour, more classmate support, and fewer post-traumatic stress symptoms, such as intrusive thought and avoidant behaviours. (2006:111).

Participants who told sexual partners also spoke of benefits. As Ruth recalls:

Ruth: Telling him made me feel much better, much better, I feel so much better. One because he knows so it's a massive weight off my shoulders, I've never felt any more pressure in my life than this, exams were nothing. I kept thinking to myself, I'd rather not get the exams than he reacts. I kept thinking 'How am I going to be if he reacts like..? I kept thinking like that because it was more important to me because I felt that I was going to ruin my self esteem, my confidence and that would demoralise me.

I was really scared about, because I was thinking 'Look if he reacts in such a sad way I'm going to completely lose it'. Because I know that I'm going to start thinking, because I'm not going to know how other people in the future's going to react. I'm going to think everyone else is going to react like that. I'm going to think...I'm not going to be able to get into a relationship, one, I'm not going to be able to have children, two.

So I thought that and that's really and truly that's what I think about the future. So that would have made me very demoralised, very much depressed. I would have been very upset. But the fact that he reacted well helped, helped a lot. Because now I've told him, I actually speak to him a lot more to him actually now, because he comes to me, he talks to me about it. He asks me how I feel, he asks me what I think, he asks me about it. And I can respond and he listens as well, whereas before then I didn't really speak to anyone about it. I wouldn't.(aged 20yrs).

Ruth links the fear of anticipated rejection to her self esteem and confidence. These appear fragile and her need for validation of her identity rests on another person's approval and acceptance. Disclosure can both cause and alleviate stress; although they fear that those they have told may tell others, this is accompanied by relief that they have told someone. Ruth now has access to greater support from her partner because she can talk to him about HIV.

Whilst providing support and care are common elements in participants' accounts of the benefits of disclosing to friends and partners, some participants recalled partners increased concern over their health. Charlotte reflects:

Charlotte: I think he values me a lot more, trying to find the words is very hard but...he's coped with it very well. He's..the word that keeps cropping up ..protective. He comes with me to all the doctors meetings. He asks me exactly

what's going on or what exactly does this number means and is it better than the last number or is it worse. And he'll ask me will that number change at all and if it does what will it mean. He likes to know. He just really seems that he wants reassurance that I'm ok. (aged 19yrs)

Partner's concerns over health and interest in test results and treatment can act as a reminder to participants of their ill health and reinforces the unspoken fear that their life span is limited. Charlotte's description of her partner wanting all her test details and results may reflect her anxiety about her deteriorating health and the reality that she is seriously ill. Partners may need reassurance from the young person, but when their prognosis is very poor reassurance is not always possible. Once a diagnosis is shared, reassurance and support are required by partners as well as participants.

6.10 Summary

Disclosure decisions are complex and risky for young people. In this study approximately equal numbers of young people decided to tell, or not to tell, another person. Whether young people tell or not their biography is disrupted by the decision-making process. Those participants who told identify three key risks in telling: the risk of rejection, the loss of control and autonomy, and, for young men, the risk of criminalisation. Young people acknowledge that relationships need to be trusting and safe when considering disclosure, whatever the context. Because of the stigma of HIV young people fear peoples' potential reactions and have to weigh up the risks and benefits of telling. Participants' motives for telling others include the need to tell using opportunities that arise out of others disclosure of HIV, and the desire to protect others in sexual relationships.

It is possible that telling others increases the opportunities for supportive relationships and telling another person provides the opportunity for acceptance of stigmatised identity resulting in validating self. The relationship between stigma and identity is illuminated in

the disclosure process for some young people their stigmatised identity does not dominate all interactions, but for others it can do so. Disclosure can bring the separated parts of identity together and results in an acceptance of HIV as part of a young person's biography.

Thus telling others about HIV status can bring both benefits and problems. For example, some young people cite the loss of control and autonomy as a significant issue which can result in others being told without their permission. Unintended disclosure by friends and family can also create difficulties for young people who have to cope with their HIV status becoming public. Participants also acknowledge some benefits of telling friends and partners; these include, relief and, reduction in stress and anxiety. Disclosure can also result in opportunities for greater support, care, and friendship. For many participants a lot of energy is expended in keeping their HIV status secret and as some pointed out, maintaining silence around this issue, encourages and reinforces the stigma around HIV in society (Michaud et al. 2009).

Chapter 7

Making sense of HIV

7.1. Introduction

The process of making sense of HIV is a process that takes time and participants do this in various ways. Young people attach diverse meanings to their experiences of HIV infection to enable them to live in a way which is consistent with their life circumstances and experiences. HIV brings with it a set of physical and psychological challenges for young people and disrupts their views about their future, health, control and meaning of their lives (Bury 1982). The primary challenge for participants is their ability to ascribe meaning to the HIV experience, and to re-formulate their place and role in their world in light of HIV.

This chapter is concerned with how young people make sense of HIV by considering six narratives or accounts which have been identified from the interview transcripts. Young people do not have one fixed narrative, some move between different narratives and as the disease process changes narratives may alter and as young peoples' circumstances change their narratives may also change. Because participants are in the process of transition to adulthood their narratives are dynamic rather than fixed. As noted in chapter four, Kubler-Ross described five stages experienced by people facing death, which were neither chronological nor singly experienced nor time bound; likewise young peoples' narratives are fluid.

The first is a 'religious' narrative, which may reflect a family narrative where young people look to God for a reason or explanation for their condition. Second, a 'rationalising' narrative which explains how some young people lessen the severity

of HIV by rationalising that 'there are others worse off than me'. The third narrative explores a 'redemptive' theme where young people make sense by wanting to make a difference. Fourth, is a positive narrative that is represented by a changed worldview, which explores how young people focus on the positive personal changes that HIV has brought about and their changed outlook on life. The fifth considers the 'narrative of the past', the story of how young people became infected and the sixth and final narrative explores their 'future', how HIV disrupts taken-for-granted assumption about a hoped for life. Each of these narratives entails a characteristic set of themes, images and metaphors which serve to construct the experience of HIV infection in very different ways.

7.2. Religious narrative

Making sense of HIV using a religious narrative may reflect an individual's belief and value system and the cultural context within which young people grow. It may reflect a family narrative that young people extend to make sense of HIV. For some young people in this study, religion was extremely important and those that describe a religious narrative identify themselves as coming from a Christian tradition predominantly, citing parental belief and religious adherence within families. This may be a reflection of the cultural mix of the sample as over 50% of young people come from Africa where religion is a more prominent part of family and community life than in Western Europe (Becker and Wenzel 2007). Ridge and colleagues (2007) found that religion and prayer played an important role for black heterosexual women and men with HIV in London (Ridge et al. 2007).

Why did God pick me?

Making sense of HIV often involves asking the difficult question 'Why me?' and those that have a religious frame of reference ask the question of God.

Denisha: Hold on, why me? ..I'd be like why is it me that's always got to go through this? Out of everyone in the world, why did God pick me?...if God's all loving and all knowing and all that stuff, yeah, why do you get disease in the world, sort of thing, so I think why do you get disease in the world and the people can argue that with saying 'God didn't make HIV, HIV was man made' like someone somewhere made it sort of thing. But I was like, 'Fair enough, you say that but God gave them the minds to make it so therefore is God all loving or is he just testing people to see if they can go through it?' That's what I see like, my life's a test, lots of tests to see if I can get through them or not..... When I'm ill I think that's a test. I see it as God punishing me rather than, no God's not punishing me. And it's just like, well if there is a God why is he not helping me, sort of thing, cos they say God's like meant to make you better and you are meant to pray to him to make you better, but I haven't seen the signs. (aged 18yrs)

Denisha looks for evidence of a just world and a just God. She rationalises the tension between a loving God and the fact she has HIV infection. She views her condition as both a test and punishment. Despite her disappointment with God, Denisha still looks for signs of God making her better. Atkins and Ahmad (2001) found that young people with Thalassaemia used similar concepts such as God testing or punishing them to make sense of their experiences, and they found spiritual belief helpful. Other studies with adults with HIV (Jacobson Jr. et al. 2006; Barroso and Cope-Powell 2000; Plattner and Meiring 2006) have also found that religious and spiritual meaning-making are commonly used to help make sense of HIV.

Denisha explains her responses to the stigma of HIV from a religious perspective:

Denisha: God doesn't hate the sinner, he hates the sin, so therefore if the HIV is a sin they (friends) shouldn't hate me, they should still get to know me and think I'm a nice person. (aged 18yrs)

Denisha thus uses a biblical reference to explain her fear of rejection from friends.

Similarly Louisa reflects on why she has HIV:

Louisa: Death doesn't frighten me anymore, it's just the whole thing hits me and I think Oh God, I have HIV, Oh God, my mum has HIV, Oh God, my dad has HIV and why? I always have the whole whys in the back of my head like out of all of the brothers and sisters, why is it only me God? (aged 17yrs)

Louisa looks for some rationale to explain the unfairness of her siblings not being infected. Her frame of reference is constructed, like Denisha's, around the idea of a just world and a divine God. Even an apparent acceptance of the fear of death is overridden in the search for some fairness and an explanation from God.

'God gave me that for a reason'

Lakeesha exemplifies those young people who believe that God gave them HIV for a reason:

Lakeesha: I know it's so weird, but you are special and I feel – I'm not religious – but I feel the idea is that God gave me that for a reason and you can't always go around life thinking 'Oh I've got this, what am I going to do about it? I think it's like you've got it, you can deal with it and it can be a good thing as well. (added 17yrs)

Lakeesha believes that she has been chosen for the difficult task of having HIV. Studies with young people with Thalassaemia and cancer provide similar narratives suggesting that God would only give illness to those who had the resources to cope with it (Atkin and Ahmad 2001; Stewart 2003). Not only has HIV been given to Lakeesha for a reason, she further reframes HIV as a good thing. Making sense in

this way helps reconcile a stressful situation with one's own beliefs and values and helps Lakeesha regain control of her situation (Plattner and Meiring 2006). Later on in her interview she explains why God let her have HIV:

Lakeesha: I think of it as God letting me have it, cos I'm one out of four who could have got it. Cos it's like, man can't determine what's going to happen and God can. It's not that I'm religious, but I still think that way. So it's just God made me have it for a reason. God didn't let them have it for a reason, and I accept that fact....it's like cos without that I wouldn't be the person I am now.

I said to mum, I think she was blaming herself 'Oh mum God gave it to me for a reason, now you're starting to doubt that – you're doubting that there's a God, you're saying that you can change things, but you can't. Josh and Sam (brothers) haven't got it cos God didn't want them to have it. You've got it cos there's a reason for it and I go 'You can't change like what God's done. You're trying to make it reversible' and you can't with God. (aged 17yrs)

Attributing HIV infection to God gives meaning and purpose as well as hope to Lakeesha. As the only child with HIV of four Lakeesha believes that HIV is part of God's plan for her. Any challenge to that premise is unacceptable, as it would threaten the very foundation of how she makes sense of HIV. Lakeesha views her mother as questioning God's power by raising her own role in passing on HIV infection. She believes that no-one can change the course of events if ordained by God, and her siblings not being infected is further evidence of both God's power and will, but also her destiny. Other studies reveal similar findings. For example, Baumgartner (2002:50) observed that adults with HIV ascribed a religious rationale for their infection, believing HIV was 'part of God's plan', which gave a purpose and meaning to their HIV status. Plattner and Meiring's (2006) study found that adults with behaviourally transmitted HIV accepted their status because they blamed

themselves; they spoke of 'personal deservedness' and saw it as a test or punishment from God.

However, making sense of HIV within a religious framework can also bring difficulties. Jonas whose HIV infection had resulted in a serious problem with his leg, which affected his mobility and ability to walk, recalls his family's response following surgery:

Jonas: I asked my Dad 'Do you think I can walk?' He said 'It's in God's power'.....and my aunties kept saying 'It's possible, God can do it, God can do it', I was like 'I believe this', but maybe this was how I supposed to be.
(aged 16yrs)

Living in families where there is a belief that God will heal can be difficult when healing does not happen. Being able to find a reason for pain and suffering is necessary for most young people, particularly those who have experienced serious illness and have limited life expectancy (Barroso and Powell-Cope 2000; Plattner and Meiring 2006). Explanations rooted in a religious framework offer some young people comfort and control. It also contributes to a sense of purpose and can give meaning and significance to a life that is characterised by suffering and difficulties, as Elijah reflects:

Elijah: What helps is the bible, 'cos I believe that all this is for a reason. It's not in vain, I wasn't born HIV for coincidence or for a joke, I'm not blind in one eye for no coincidence and no joke. I don't live this secret double life for no coincidence or no joke. They're all for a greater purpose innit. It's all for a greater thing innit like. For his kingdom innit basically innit, so it's just about everyday asking him 'What do you want to do with me today? What do you want to do? What's the plan? (aged 20yrs)

Religion helps Elijah make sense of HIV. Elijah's belief provides hope and reassurance that his suffering is part of a greater plan and purpose, and gives his life direction. His belief enables him to accept and explain his situation, and enabled him to carry on living in very difficult circumstances.

In the following extract Elijah recalls when he decided to stop taking medication.

Elijah: It was like Jesus, like God, I started to realise and started to clock the patterns..like how he was actually giving me so many chances, every time I got to the edge of a cliff pulled me back, sent some kind of angel, sent some kind of warning....he had to take everything away from me for a second innit to make me realise...God blessed me with the right people, put the right people around me innit and he took them away kind of thing. (aged 20yrs)

Elijah interprets his difficult experiences within his religious framework. The pain and sadness is seen as something that will ultimately benefit him, and reflects his belief that God has ultimate control of his life. Elijah's faith enables him to believe that he will be protected and taken care of and that whatever happens in his life, however difficult, it is for his own good.

Some participants' religious beliefs helps them understand how they became infected. Elijah reflects on his parents:

Elijah: I used to blame them, but not anymore, 'cos they were naïve and young themselves and God like, God did this for a reason innit, he's going to use this in a positive way, and like this has completely reshaped my attitude innit. (aged 20yrs)

Whilst religious narratives are used primarily in terms to help make some sense of HIV, they also offer comfort, as Louisa reflects:

Louisa: I think my main sort of rock was in Christianity was actually right...there was prayer as well cos praying constantly like 'please God help me and don't kill me' and all this stuff (laughs). (aged 17yrs)

Religious beliefs can support young people at difficult times. Studies such as those of Kyngas and colleagues (2001) have found that Belief in God or Allah has been cited as one of the major resources for young people coping with cancer (see also Stewart 2003; Atkin and Ahmad 2001)). Louisa uses prayer as a resource to help her cope with being scared and her fears about dying (Ridge et al 2007). When faced with uncertainty Louisa's religion provides the support and a fixed point of reference that is reliable and secure. Several young people, particularly those who have experienced disruptive family life, such as Rebecca found belief and faith supportive.

Rebecca came to the UK from Zimbabwe when she was twelve and left the family home in the UK when she was fourteen; she now lives in a hostel and has little contact with her family:

Rebecca: Whether you've got HIV or not God loves us which is the main thing innit. What else is there? (aged 17yrs)

God loves Rebecca in a life where she perceives few other people do. Other participants, such as Joshua cite love and hope as key benefits of faith and religion.

Joshua: Hope comes from religion as well, having that helps, when I go to church there's a little release. People don't know in church, but it helps, praying and stuff. (aged 22yrs)

Participants' religious narratives show that, for some, having a belief offers reassurance and comfort, as well as a way to make sense of having HIV. As young people have to accommodate to the uncertainty of HIV religion provides them with a way to view their condition as having some purpose. They may relinquish an identity

as someone without HIV but, gain an identity as someone who is HIV positive. The role of a religious narrative in maintaining and developing an identity with HIV connects participants with their existing family narrative and offers comfort and hope. A religious narrative gives value to their experience and in turn gives worth to this new part of their identity.

A religious narrative provides answers to the difficult question of Why me? a familiar framework to address the threats HIV brings to a person's sense of identity and offers an explanation for suffering, pain and death.

Young people who grow up within a religious family narrative preserve a link with their past by adapting it to make sense of their altered situation (Charmaz 1997:49). Religion provides them with the continuity of past belief and future hope retaining part of a previous identity. HIV may not bring drastic life-style changes for young people however it may limit their potential future roles and identities. A religious narrative minimises the biographical disruption for young people as it is an already familiar and established narrative. HIV is re-interpreted within this comfortable and safe narrative.

The 'rationalising' narrative where HIV is not viewed as the worst thing in the world is considered next.

7.3. 'There are others worse off than me' - Rationalisation narrative

Many young people make sense of HIV by rationalising the severity and implications of the disease. The rationalisation narrative serves to minimise the impact of biographical disruption due to HIV because whilst 'others' are in a worse situation ones own situation is perceived as 'not that bad'; others are further down the hierarchy of suffering. By identifying another group or individual as suffering more than oneself or as more stigmatised than oneself, the impact of biographical disruption is reduced and an identity of worth is maintained. Young people identify

the stigma of HIV as one of the most difficult aspects to manage and this may have more impact on young people than the physical effects of their condition (Flowers et al. 2006) as it influences the way they understand themselves and their new identity; it is the stigma attached to HIV that young people want to distance themselves from rather than the physical aspects of HIV.

Being reminded that there are others worse off lessens the emotional impact of HIV and provides young people with a wider perspective on their situation, as Rebecca explains:

Rebecca: Don't look at yourself as cursed, because you've got an illness, you know what I mean, just keep your head up, to be honest really, cos really things could be worse, I mean come on, you've got people with no legs and people with no arms and if you've got HIV you're still able to do stuff, even if you're not able, but the fact that you are alive innit, just kind of like thank God for what we have, man you know what I mean. Obviously it's one of the deadliest diseases, well not yet, but right we have got doctors to help us with all that, so it's not the end of the world because you've got a virus, maybe it's a new beginning. (aged 17yrs)

Rebecca sustains a sense of normality by comparing herself to others worse off than herself, but this casts others as 'victims', a definition that many participants strive to resist themselves. Her access to a positive identity is limited because of the stigma associated with being HIV positive however; by comparing herself with a more negatively valued group she is able to gain a positive sense of identity (Joffe 1999:34).

Denisha and Joshua express similar sentiments:

Denisha: I'm not saying that I'm really the worst, cos I know there's people out there that are worse than me, do you know what I'm saying, there's

definitely people out there worse than me. So I'm not saying my life is completely pointless or that I can't cope with it cos I know I'm not the only one that's got suffering, I know there's people suffering more than me cos they aint got no education to do anything about it. Or aint got no condoms to stop spreading it. (aged 18yrs)

Joshua: I don't think it's good to try and make HIV a reason to not enjoy your life, it is still possible for you to have some happiness...there's worse things than HIV anyway, so there's worse things in the world than that...it's not the worst. (aged 22yrs)

Joshua's wish for 'some happiness' may reflect his difficult life experience. He came to the UK from Uganda when he was five having lost both parents to HIV. He spent his early years living in bed and breakfast accommodation with his sister and has experienced quite compromised health for much of his life.

Similarly rationalisation helps Mark and Catriona manage HIV:

Mark: Trust me there are hundreds of people who are living with HIV and even up to the age of eighty, you can live a good life if you look after yourself...you will not die straight away...you'll still die from HIV but it's not as bad as people make it out to be and I am someone who is speaking from experience, so I would know that. (aged 18yrs)

Catriona: At the end of the day if you've grown up with it like I have it's just a thing you have to deal with, you can't shut the door on it or think it's going to go away because it won't, but at the end of the day I think the more you come to grips with it .. and think of it as it's not really that bad, but it's not the worst thing in the world. (aged 17yrs)

Rationalising their HIV status enables Mark and Catriona to gain some control and maintain a perspective that helps them manage their day to day life. In making

sense of HIV young people take stock of their identity and their purpose. Their previous views may be challenged and new perceptions of the world and themselves emerge.

Some young people make sense of HIV by focusing on helping others and display altruistic tendencies. These redemptive narratives are considered next.

7.4. 'I want to make a difference' – Redemptive narrative

Some young people find HIV presents an opportunity for self-development and to help other people. These redemptive narratives include wanting to change the world, making a difference to the lives of others and using a diagnosis of HIV for the benefit of others. Several young people participated in this research because they 'wanted to make a difference'; they hoped their participation would alter how people view and treat young people with HIV. This narrative contrasts with the previous one where participants' engaged in the process of rationalisation whereas this narrative presents HIV as a motivating force.

Having HIV does not necessarily mean that young people are more likely to demonstrate altruistic motives than any other young people, but for some participants find meaning in this situation. Matthew reflects:

Matthew: I want to be a doctor..I want to do research into drugs for HIV. I want to help people cos I've met people with it and I know they don't deserve, well they deserve a full shout at life, you know just as much as I had...I'd love to be able to change that.(aged 18yrs)

Baumgartner (2002) extended previous research (Coutenay et al. 1998) and found that adults with HIV experience a 'perspective transformation'; individuals had re-evaluated their assumptions about life and had a new world view in light of HIV which was sustained over time. Similarly Schwartzberg (1993) observed how HIV positive gay men made sense of HIV by developing a 'higher meaning' to their life,

characterised by empathy and altruism. Baumgartner (2002) found that participants sought opportunities to make a meaningful contribution, and a need to be of service to others.

Similarly some participants, like Charlotte wanted to make a difference:

Charlotte: I'd quite like to be a psychologist and I suppose you could read into that that my way of viewing things might....I suppose empathy for others was developed by seeing a different side of life...my life wasn't just about going to the cinema and meeting friends ..I had other things to deal with and forced me to think about bigger subjects as HIV is no small deal...you're sort of required to ask big questions and think big thoughts that teenagers generally don't do..... death is an obvious one, intimacy is another, your future is also one...coming to terms with each of those and how my life will be governed because of my different circumstances. (aged 19yrs)

The experience of living with HIV influences some young people's attraction to pursuing certain careers. This response has been reported in relation to young people with other life limiting conditions (Baumgartner 2002; Courtenay 2000; Kyngas et al. 2001). Charlotte may have wanted to be a psychologist had she never had HIV infection, but she may have been influenced by her experiences and exposure to the care and support services, and consequently developed 'empathy'. Facing issues such as one's own mortality may influence young people's choices about their future. Being attracted to a career that makes a difference to the lives of others may be a response to finding a way to give her life meaning and significance. As Courtenay and colleagues observe: 'the prospect of death at an early age challenges assumptions and values about the meaning of life' (2000:103).

Making the most of life and pursuing careers that are perceived to make a difference and leave a lasting legacy matter to some young people. As Louisa reflects:

Louisa: I want to live a life that is full, live it properly. I just want to succeed in the future as best as possible and I definitely want to help people. Because the time I found out after about five months I thought, you know stop beating yourself up about it and get up and do something. Get up and help someone because there a lot of people that do need your help....I want to make the most of my future. (aged 17yrs)

Participants' motives in pursuing a fulfilling career mainly centre on trying to make sense of HIV through helping others and this may reflect a need to make a contribution in a life that may be limited. Louisa links helping people and a life of worth and significance. This motive may be stronger for young people who have any life limiting illness, not necessarily HIV (Crew Nelms 1989).

Whilst there is not necessarily a causal connection between having HIV and altruism, the connection may be one of identification and empathy with others who are in similar situations as Matthew reflects:

Matthew: I want to one day find drugs that'll help other people who've got HIV, leukaemia most definitely, and malaria obviously, that's a huge problem...I'd love to do stuff with my life and the reason I'm so interested in leukaemia is because of a programme that I watched called 'Children living with childhood cancer' had this boy called Peter and he was similar age to me...wanted to do lots with his life and one day he fell ill, you know he was told he had leukaemia and the screen went blank and it said in white writing 'Peter died two weeks later'.

It was awful and that's primarily why I want to be a doctor, cos I felt a connection, because I'm the same age, I do similar stuff to him, I want to do stuff with my life but he hasn't had a chance and I'm still here. I'm still sound, I'm still strong and you know everyday I think it's weird, now I'm taking the drugs I'm more grateful for my life than I was before..... because like other

people, you know the third world don't get these types of drug. You know, what's the point ? I mean I really felt that hit me, cos that could have been me and you know I've done so much with my life and there's so much more I can do with my life and, you know it hit me, it kind of is very much I owe it to him, I feel I owe it to him in some respects. I feel bad if I don't. (aged 18yrs)

Matthew clearly identifies with Peter's situation. The uncertainty of illness and the possibility of an early death resonates with Matthew and connects him to Peter's story. However, Matthew is still alive and able to make a difference which he now constructs in part as a legacy to Peter. Peter's story highlights Matthew's potential and his opportunities, but also acts as a reminder of his own mortality. For participants like Matthew there may be positive benefits of doing something to make a difference. Being valued and making a contribution to others holds great power and attraction. As Matthew explains:

Matthew: The thing I've always dreamed about for a long time is to be able to stand up one day and hold a jar, a little vase or something, with like a solution or a pill which is the HIV cure. That's the one thing I've just dreamt about for so long now. To say, you know, of the disease there are loads of people out there who've got it and they fight every day against you know, prejudice, and discrimination and today is your day, you know. You stood up and you can be counted for, and I've wanted to do that for so long and I will do that, one day I will do that as a doctor....I would love to do that, not to go down in history, but be able just to live, just to exist. (aged 18yrs)

Matthew links legacy and mortality and identifies the prejudice and discrimination meted out to those with HIV. His need to be recognised as someone who stands up for what he believes in is a significant element in his account.

Finding a cure will enable Matthew to publicly reveal his status which he feels currently unable to do. Without a cure Matthew's life remains unpredictable and he feels unable to challenge the prejudices that surround HIV, and he has no control or power over his own situation. Matthew's account sustains the theme of legacy as he wants to be the one to find the cure, thus being remembered for doing something of historical significance.

Baumeister observes that meaning-making in the face of possible death is often characterised by the meaning being embedded in contexts broader than one's own life: 'If one can invoke a context that will outlast one's life, then one's accomplishments will have meaning even despite one's death, they will not be futile' (1991:175). Participating in this research for some young people was a matter of legacy, recording their story in order to have their voice heard and remembered. This was particularly poignant for those young people with limited life expectancy.

Some participants verbalised leaving a legacy in relation to working in developing countries, for example Louisa, whose family originally came from Uganda. Her aunt died from HIV:

Louisa: I had a like a big future plan, last year I went to Uganda at Christmas and I saw a lot of people especially young children who had HIV. And in Uganda obviously like they don't have the sort of resources we have here and medication and stuff like that and I thought to myself, that was one of my late auntie's decisions, she basically had a big plan to build a clinic in Uganda for, you know for children with HIV, for them to you know get the medication and get some sort of counselling and get some sort of help. But she did not live long enough to get medication that could have helped her live. So I thought, that's exactly what I want to do. I want to teach other people how to deal with it and I want to know how they deal with it as well.
(aged 17yrs)

Louisa feels responsible for keeping her aunt's memory alive and wants to help others with HIV. She hopes to establish something of significance for others with HIV, and also potentially find out how other people manage their situations.

Overlaying the desire to make a difference is the realisation that life is likely to be shortened by HIV which exacerbates the urgency of leaving something of value behind. This may be motivated by need to be remembered by something positive rather than the stigmatised condition that they have. Whilst some participants are motivated to make a difference, others find that the biographical disruption of HIV has changed how they look at the world and their outlook in a positive way. HIV has changed their identity and this has led to a reconstruction of a new identity in light of an uncertain condition (Pierret 2000). How young people re-construct HIV and their identity in a positive way is considered next.

7.5 'HIV has changed me in a good way'. – Positive narrative; a changed worldview

The stigma attached to HIV impacts on how young people see themselves and trying to re-define a stigmatised identity is a challenge because of the negative social discourse that has developed around HIV. HIV disrupts biography and some participants reflect on how HIV has changed the way they look at the world and their identity, and surprisingly several describe positive aspects of having HIV.

As Lakeesha explains:

Lakeesha: HIV actually hasn't become a burden now. It's become more like, I don't know, I'm quite proud of being HIV positive.... I don't know what the downside is cos I accepted it quite early on... I'm quite grateful as well. This sounds really twisted, I'm so happy that it's me that's got HIV and not my little sisters. Cos an odd chance that mum's got four kids and then I'm the second child and it was me and not them three. Cos she didn't know about

her status and my dad didn't catch it as well. So I'm just happy, cos I don't think my little sister and my brother would be able to accept the fact they would have it, cos it's how they are. They're quite a kind of person it would destroy them, so I'm quite happy that I've got it..... I think I'm really quite lucky. (aged 17yrs)

Playing down the negative aspects of HIV and positively re-framing helps Lakeesha make sense of her situation and provides a purpose in having HIV infection. The stigma of HIV is the burden for Lakeesha as she has been physically well. Considering the benefits rather than losses that HIV brings sets Lakeesha above her siblings, and, for this she is grateful. Developing a positive narrative has been observed as a valuable coping resource in studies with young people with Thalassaemia and sickle-cell (Atkin and Ahmad 2001; Kliwer and Lewis 1995). Changing a worldview in light of an illness may limit the impact and enable young people to maintaining some control over their life (Frydenberg 1997). Maintaining some control over the impact of HIV may act to minimise biographical disruption for young people and help them maintain an identity that is not stigmatised. Developing an identity that is based on a positive view of HIV distances the stigma from the individual; re-defining the condition as one that brings benefits and enables a new outlook strengthens a positive view of self.

Some participants like Ruth, view HIV as a catalyst for growth, self- discovery and personal development:

Ruth: In some ways I don't think of it being a bad thing, I just try and think of it as a good thing. Like maybe it's given my life some structure, some meaning, it's made me focus on my own goals a bit more...enjoying my life and making sure the right people are around me...you look at things differently. HIV has made me think about life a bit more, make sure I'm with the right person, make sure I enjoy my life a bit more, I'm more

disciplined..but now I think 'Oh I'm ok, I'm fine, I can live with this, I can do whatever I want to, nothing is holding me back..HIV has brought structure to my life and other valuable things, but sometimes I don't know whether it's cos of HIV's made me that or whether it's just my personal traits.(aged 20yrs)

Ruth identifies the tension between separating out her response to HIV and her own personal character traits. Ruth may well have developed a meaningful and structured life without HIV. She values the contribution HIV has made to her life and has chosen to focus on this rather than the difficulties. Participants who have lived, like Ruth, through a time when treatment for children was limited may view their lives more positively. As Ruth explains:

Ruth: People think HIV is a death sentence or people think there is no treatment, what ten years ago and your life was a very short span whereas there is now more hope. If I was living back then I would be like if I could have ten years more, if I was to have five more years, I would do this, I would do that. Now I'm thinking I've got the chance to let me do that. I've got that chance. Let me be the best friend I can be, I've got that chance, let me be the best daughter I can be. So that's how I think of it. (aged 20yrs)

The advent of new treatment for HIV has enabled Ruth to live longer and given her a second chance to be a better person. This has been described as the 'Lazarus effect' (Rabkin et al. 2000) where people previously ill with HIV experience miraculous improvements with the new treatment available over the last ten years. The impact of new treatment has changed Ruth's view of life (Barroso and Powell-Cope 2000; Plattner and Meiring 2006). This changed worldview includes putting life in perspective, re-ordering life's priorities, and finding unexpected strength.

As Elly, Lakeesha and Charlotte reflect:

Elly: I think having HIV sort of has changed me because I'm a different person because I have it sort of thing, and I wondered would I be the same person if I didn't have it sort of thing....I think I understand some things more..(aged 15yrs)

Lakeesha: I like the way it's kind of made me think about things...cos if I broke up with a boy..I don't see it as if it's like life ending....I think it has made me strong. Cos I've seen what can be devastating and stuff and like being told you're going to die is quite devastating. But it made me think of other situations as like not that harmful and upsetting. I like the impact, that's why I think of it in a good way it's affected me. Cos I think it's good I feel like that. (aged 17yrs)

Charlotte: I've learned to be independent and fairly fearless (laughs) Again and again I notice in myself the ability to brush aside petty little things like if I have a bad hair day. It's not the end of the world. And if there's something scary that has to be done, like jumping into a cold river or something like that, then there's nothing really to be afraid of. It's given me more bravery. (aged 19yrs)

HIV brings personal changes for young people they did not expect. It seems that biographical disruption is not always negative (Exley and Letherby 2001). Asbring (2001) found that there were illness gains in relation to a new identity as well as losses and in my study this may also be the case. Whilst Bury did not specifically identify positive aspects to biographical disruption, young people report in this study that HIV has changed their outlook on life and profoundly changed their identity; for some this has been a positive change. This could be seen as merely making the

best of a difficult situation however, HIV has engendered changes in identity that some participants perceive have been personally beneficial.

The emotional impact of HIV is powerful and a shock to young people, but for Lakeesha it acts as life-affirming because she has survived its effects. Managing an HIV diagnosis demands emotional resilience and strength for most young people and comes as an unexpected consequence. Charlotte may well have been brave and fearless without having HIV, but HIV has put certain demands on her and consequently she developed a set of skills to respond to these. HIV has disrupted the biography of these young women and has changed their circumstances, and it is their responses to the circumstances rather than just to HIV that enables them to make sense of their condition (Bury 1982).

Young people have had to develop or find the resources to deal with the disruption of HIV. Whilst developing a positive narrative is a reflection of personality and character, it also depends on circumstances. A positive narrative HIV can also provide an emotional opportunity for young people to consider other aspects in their life.

Elijah has experienced a complex and difficult life, he reflects on how HIV has altered his worldview and changed his identity:

Elijah: HIV has shaped me innit. It's made me who I am today innit. But it's about your focus and how you apply it innit. Cos you can make it shape you and make you miserable and make you sad and make you angry and be it with the world innit and just depressed, or you can use it to full advantage and say 'Do you know what?' This life is only temporary anyway and at last you're going to die innit, we're all gonna die. So you can just get on with it and have as much fun as possible just as much as in that sky innit. It's how you apply yourself innit.(aged 20yrs)

Developing a different philosophy on life helps puts other issues that may worry participants into perspective and limits the disruption of HIV, as Jahia reflects:

Jahia: I've become understanding, looking at it (HIV) in a different light, in a different way...looking at the glass being half full, not seeing it as half empty. Not thinking the worst, cos it could be worse..it makes you feel like you can understand people and be more considerate to more people and help more people. It gives you that chance to use it to actually help others. It does change you. (aged 15yrs)

Experiencing illness or a serious condition, such as HIV, can result in an increased awareness of other people's needs. Jahia has developed a heightened sensitivity (Baumgartner 2002) and awareness of others. Courtenay and colleagues (1998:138) found a 'perspective transformation' in adults with HIV where their worldview changed; they reported greater sensitivity to others, being more caring, compassionate and stronger. In a later study of the same individuals (2000) they found these changes had been sustained and added to over time. They found 'increased appreciation for the human condition and the frailty of others' (2000:53).

The development of a positive narrative is usually accompanied by a re-ordering of priorities and general outlook on life, but is influenced by individual circumstances. Participants such as Paul, whose family have all died, his mother and brother from HIV, his father from other causes, reflects on how having HIV has changed his worldview:

Paul: I want everyone to know that ill or not ill, you can do whatever you want, whatever you want if you put your mind to it...you can actually have a life and do things...I think that the memory, your memories, .. I've learnt that everything is precious.... particularly living, I don't see HIV as a bad thing,

never ever, never, never ever, I don't see it as a bad thing, I don't see it as stopping me from doing anything.... (aged 24yrs)

Paul has managed to take control of how HIV has affected his life, by positively re-framing it to find meaning. Trying to limit the negative impact of HIV enables Paul to create a worldview where his life is of value not lived in vain. Despite his loss and suffering he has found a way to make sense of life with HIV (Atkin and Ahmad 2001; Frydenberg 1997).

Some young people observe that narratives about their past are incomplete. The story about the beginning part of their life is missing, particularly where a parent has died.

7.6. 'I didn't get given any memories' – Narratives about the past

Some young people make sense of HIV through interpreting narratives about their past. Most describe a reluctance of those around them to talk openly about their early and past biography. Young people's stories are unfolding and change with events, and their past biography is based on the available information and the social scripts they have been given (Good 1994).

Becka lives with her dad and step-mother, and has had no recent contact with her mother who lives in Africa:

Becka: He (Dad) never talks about her either and I think that's why he finds it hard to talk about it... but I think it hurts him a lot to remember it.

I don't know if he blames her, because I don't know how, I keep meaning to ask (laughs) and you know if it was on my file or anything, but because I haven't asked questions for so long I don't know how my Mum got it initially, and so I don't know if it was her fault how she got it. I mean that

sounds a bit harsh saying it was her fault but there are ways of avoiding getting it, if I knew that I could sort of piece it all together a bit better and understand.

...it would solve things a lot better and just sort of, another bit to finish the story of my mum, ..and me. I would definitely like to find out how she got it because, yeah, because I think, I mean it's a bit late now..but it would help me make sense of my life now..(aged 17yrs)

Some participants emphasise the importance of knowing the actual details of the beginning of their HIV story in order to make sense of their present. Becka's reluctance to ask her Dad or others around her is repeated by other participants who explain that they fear upsetting parents(s). They act to protect them and not raise what they feel are 'difficult' issues. Similar responses and fears are observed in Atkins and Ahmad's study (2001) of young people with Thalassaemia, and has also been reported in other studies of young people with cancer (Kyngas et al. 2001; Stewart 2003; Atkin and Ahmad 2001).

Thus for some young people not having information affects their ability to make sense of their present biography and their future. Becka's account positions her as having little or no control over the information she wants, and as a result she remains in an uncomfortable state of uncertainty. Other participants also spoke of wanting to know their story:

Ruth: I don't think I know as much as I need to know or as much as I should know about exactly how it was passed on to me. I don't know too much information about that, which is possibly a side want to know more but I haven't pushed it any further because I don't want to go into something..that I am too afraid to go into. I don't want to upset my mum but I mean I feel I have a right to know all the story about my dad and stuff. I mean I do have the right but I don't want to upset my mum...I want to know how my mum

caught it and possibly why my dad.... because I don't know what happened.....I just want to know a bit more and like in the beginning information. It would help..(aged 20yrs)

Information is more limited where a parent has died, like Charlotte, who lost both parents by the time she was four years old:

Charlotte: I think I would have liked to be sat down, explained the whole story of it from a family point of view. I got given the facts that 'your mother caught it from your father and you caught it from your mum, from your mother by pregnancy' I got given the facts however I didn't get given any memories possibly because they were too painful for my grandmother to think about. It was something that I've acknowledged and I won't push her, but I would like to know. (aged 19yrs)

Charlotte wants to understand her early life that included her mum and dad, as she has few concrete memories or information. She does not want to know just the mechanical facts of how she was infected, but wants to construct a memory of her forgotten family. This appears to be particularly difficult where a parent has died. Matthew's mother died when he was four and he does not feel able to talk to his father about his mother. He lives with his mother's sister who has never talked about his mum:

Matthew: Yeah I would like to find out more about her, I don't know what she'd think of me now. I think she'd be happy that I'm alive and here. But still, as bad as it sounds I feel..I don't know if she gave it to me through birth, the actual birth or through breast milk but, sometimes I wish it was just like I had been born and HIV positive hadn't been around, and I almost feel like, well not like you deserved to die because of what you did to me but, because of, you know, you owe it to me in some respects, you weren't there when I needed you, so I'll never think about you to be

honest. You know the times when I did need her and the times I really wished she was here, and she's not there... After a while it just doesn't sink in that she was once there... I don't like looking at the pictures of my mum cos they hurt me too much, but I don't know if she would be proud of me at all because I don't know too much about her..

I would like to know what did she smell like, what perfume.. or what she do with her life? I don't know if she had a job, I don't even know if she got married to my dad, I don't know how she got the disease, I don't know whether she... I know she was African, that's all I really know and she had HIV when she dies and she was my mum and that's it. (aged 18yrs)

Some young people lose a parent's life story when they die because the remaining parent does not talk to them. The loss of a parent is further complicated by how the remaining parent and family communicate and how they deal with the loss. HIV may just consolidate or complicate already existing patterns of communication in families. Matthew speaks predominantly about loss and bereavement rather than HIV. These unresolved issues can affect how young people make sense of having HIV.

As well as wanting to make sense of their past, young people think and plan for their future as many are at a stage of transition. Their narratives about their futures are considered in the final section.

7.7. Narratives about the future

Most participants' narratives about their future may not be dissimilar from those without HIV, Elijah explains:

Elijah: My future, aah, just fireworks right..hopefully good ones, but July 4th all the way like. I want it to be quality innit, I want to be successful, I want to have money and stuff, look after my family, you get me. Have the nice

houses and the nice cars and yeah, hopefully settle down, have a wife, some kids, to be happy, retire at 30. (aged 20yrs)

Elijah aspires to be 'normal'. The potential future stories for young people are based on available social scripts and their stories are not finished, but are influenced by having HIV.

HIV infection challenges most young people's taken-for-granted assumptions about their life and their ideas about an anticipated life course. Charmaz (1997) and Bury (1982) identify how all chronic illness affects assumptions about a future life course. Particular aspects of HIV are perceived to impact on their future.

'I may not have children'

Participants fear the loss of a conventional life course trajectory, particularly in relation to relationships and having children. As Joanna reflects:

Joanna: I don't know how I see my future cos it's changed since I found out I can't have a family, it was, it would have been the natural, get a good career and then go travelling the usual. ...I found out like I'll never have a family and probably never get anyone to marry me or anything and it's just quite hard cos you're like, you'll just be single for the rest of your life.. Cos I've always wanted my own family but cos of what I've got it's sort of messed up my growing and stuff and I had a very nice doctor, he very kindly told me I was infertile and I wouldn't have kids, but she said it so matter of factly and then went on to something else. And that's kind of knocked it completely back 'cos while I'm like I've got HIV and the next one I can't have a family, which is what most guys want I guess..

I felt awful and I still feel really bad about not being able to have my own...and when my sister went into labour and it kind of brought it all back that it will never happen to me. (aged 18yrs)

Joanna's perception of her own future contrasts with her perception of those around her, her sisters and her friends. HIV has interrupted Joanna's "normal" life course and pattern and has disrupted her present as well as her future biography (Bury 1982). She links not being able to have children to her attractiveness to men because she associates her value as a woman with her fertility. Joanna has to come to terms with a series of potential losses in her life. Drew (2003:195) identified young people's concerns over fertility and future plans for a family as a significant issue for those who had cancer in childhood. She found a gendered response to fertility with the imagined role of motherhood more prominent in young people's narrative than fatherhood. However, in my study, several young men, such as Samuel spoke about fatherhood:

Samuel: I just see a normal future, but then it's one of those futures where it's going to be difficult cos how like when it comes to the whole thing of having a family, getting married, it's not going to be a normal thing.... If you want children you have to go through a lot of things and stuff like that. So that's going to be difficult, and to find a person who's willing to go through all that is also going to be difficult..I just want to work hard and get a good job. (aged 19yrs)

Samuel, like Joanna, considers a "normal" future less likely and having children that bit more difficult. Unlike Joanna, Samuel focuses on getting a job and working hard, for him that is his "normal". This may reflect a gender difference. Charlotte also identifies parenthood as an issue, but she constructs a different meaning to that of Joanna:

Charlotte: I think mortgages are going to be hell (laughs) I think having my own family is probably not going to happen, but that doesn't mean I will never have kids because there's adoption and well, borrowing someone else's children for an afternoon, and then I suppose there's the choice of not having children at all, which I suppose is something if you feel ready to accept then you can live with. I think my job is going to be hateful on a Monday and wonderful on a Friday and other than that I'm not going to be affected by much else. I intend to live a very normal life. (aged 19yrs)

Charlotte is able to positively re-frame her anticipated loss of not being able to have her own biological family and presents alternative scenarios that could meet her desire for children. Jacob is also hopeful about becoming a father:

Jacob: Thinking about my future I think I'm paternal and I want to have you know, family of my own one day and I'm worried about, you know having kids and I was thinking about that. I was speaking to the doctors about it and they said it's not impossible, so really the future, you know I consider it more so than anything else, and recently I felt bad towards the HIV because it may take my future, but you've got to move forward. (aged 18yrs)

Although Charlotte and Jacob sadly acknowledge that they may not be able to have their own children, they have developed positive scenarios to accommodate this reality. Jacob's extract also demonstrates how HIV has taken this future away. Thus participants have to confront how HIV disrupts a hoped for life. Disruption of biography includes the realisation for young people that their lives may be cut short.

'I won't live as long as I'd like to'

Some participants reflect that HIV will affect their life expectancy and the likelihood that they will not reach old age:

Becka: I'd love to live to ninety eight or something it's sort of hold on, maybe I can't. I'm not sure whether something will one day horribly go wrong and I'll get ill ...you just don't know how long it's going to be. And I try not to think about that but because I'm thinking about the future now ...and the thought of maybe not being able to do those things that I want to do and the travelling or stuff, it worries me quite a bit and I mean I think that's why I'm running round like a headless chicken the whole time. I don't think 'Oh this time next week' or 'this time next year I could be dead' but it could happen (laughs) and that's something that will always play a part in my life. It's been a recent realisation that maybe I won't live as long as long as I'd like to. It's sort of only recently dawned on me that basically, I'm always going to have HIV and I could live for a long time or I could not, but you just have to get on with it and make good use of just sort of getting on with things really because it's so unpredictable, and there's no point of sort of counting out your days or anything. (aged 17yrs)

HIV brings uncertainty about life expectancy. Becka reassesses her life because she realises she may not live as long as she imagined. HIV has disrupted her taken-for-granted assumption of the length of her life. She manages the unpredictability of HIV by rationalising that she has no control over how long she has to live and gets on with her life. Uncertainty has been described as one of the major "stressors" faced by children and young people with conditions such as cancer and leukaemia (Brasher et al. 1998; Jessop and Stein 1985; Stewart 2003:394) and also documented in studies with adults with HIV (Courtenay 2000, 2002).

Living with HIV changes young people's outlook as Catriona reflects:

Catriona: Well I just live every day as if it's my last because you never know what could happen, so just to do as much as you can, be as happy as you can and I mean, I think at the end of the day I've got everything in the world.

I've got everything that I could ever ask for.. make sure that you live everyday as if it is your last, it won't be, but do it anyway...don't think of it as 'I'm dying really slowly' because that's what I did and I thought I'm not ever ever going to make it to seventeen and here I am now.

You just need to think of it as something like that's attached to you as that no matter what you do it's not going to go away.....you can lead a normal life knowing that your last days are going to be the happiest ones that you've ever spent because you've lived every day as if it's going to be your last, which is what I do. (aged 17yrs)

Participants live with an expectation of premature death and the uncertainty accompanied by HIV. Janoff-Bulman observed similar responses in the study of trauma victims (1999:136) where survivors found that they did not take life for granted any longer and realised 'how precious life is'. The fear of death informs and affects young people's approach and reflection on life.

Participants who experience the loss of siblings and parents develop a heightened awareness of a disrupted of life course. As Paul reflects:

Paul: When my mum died and then my brother died, it was a case of when was my turn, you know that was definitely it, so next in line is me, but I am still here. I wish my brother had been able to wait just a bit longer, so he didn't have the chance to take these meds, so in a way I must honour him and take it properly, I have the chances he didn't and I wasn't meant to live this long so I surprised everyone by living this long.. (aged 24yrs)

Living with the memories of family who have died of the same disease affects the young person's own perception of the future. Paul has a young child and the unpredictability of HIV in terms of his expected life span is focused around being there for his child:

Paul: I just think about seeing the most of him, as much as I can, that's all I can do, I just think about seeing him every day and trying to absorb him so much of him into me that I can, and absorb so much of myself into him you know, so he won't ever forget me. (aged 24yrs)

Several studies with children have shown a strong association between uncertainty and emotional distress (Stewart 2003). The uncertainty of HIV varies over the course of the illness trajectory and changes over time (Brashers et al. 1998), but is heightened because young people often have to deal with unexpected illness. Jacob reflects:

Jacob: Life isn't easy, it's a lot of work and I've got goals but I worry that you know, something might happens to me, get ill again, you slow you down to and I might not be able to do things like get a job..thinking of the future is difficult because you just never know do you...(aged 18yrs)

Those participants who have been severely ill may experience the disruption of HIV differently than those who have been asymptomatic. As Jacob explains, keeping well and holding down a job are realistic concerns about his future.

The uncertainty of HIV exacerbates the fear of dying and the possibility of a premature death as Charlotte reflects:

Charlotte: HIV has forced me to think about bigger subjects as HIV is no small deal. You are sort of required to ask big questions and think big thoughts that teenagers don't do...Death is an obvious one, intimacy is another , your future is also one....Coming to terms with death I suppose. If you're going to contemplate such big ideas that you don't usually don't think about until very late in life, you realise that early on and you're going to have more of a drive to achieve more to do certain things...I now have a

philosophy that it's better to experience a lot of things than just do nothing with your life and regret it later on. (aged 19yrs)

The 'big' issue Charlotte has to face is death. HIV challenges the 'natural order' of the old dying before the young, and Charlotte thinks about dying when she feels she should be thinking about living. HIV has restricted and shortened her life.

Denisha, who has also experienced recurrent ill health, reflects differently on her future:

Denisha: I don't plan anything because I take one step day by day..I haven't looked into the future, 'cos I don't know if I'll be living in the future, so I just take each day as it goes. I don't really plan too far ahead. I don't feel I can. It feels better then at least you can say I did that. Cos at least you can say you tried to do it, and if you don't do things you can't be disappointed when you don't get to do them, you do need that. Well I've lived my life to the fullest and I weren't planning to do things and then it hasn't come true. So I don't feel too disappointed with my life as I hadn't planned to do anything..(aged 18yrs – Died Feb. 2009)

Denisha's narrative reflects her experience of poor health. Her limited expectations of her future do not prevent disappointment, but remind her of the reality of HIV. The sense of loss and sadness in her narrative reflect her circumstances, as she was aware she had very little time left to live.

Those young people who have less ill health still express concerns over their future health, as Jacob explains:

Jacob: A couple of year ago I asked my HIV doctors about what my life expectancy and like you know there are new discoveries being made and it will be, you know quite a long time, I mean when I'm 21 and I felt at the time, you know I could look forward to being a bit more free from the HIV when I'm

21, but I've learned for me that's it, right now, I'm free from it because I'm living my life so I don't think I have to look back..just forward and you've got to take over your life as much as you can. (aged 18yrs)

Jacob has made sense of HIV by regaining some control of his life which has enabled him to focus on his future. Despite the unpredictability of HIV infection he has found a way to look forward and not back. Living with HIV for young people means living with a limited life expectancy and this affects how they view their future. Although most participants want to live 'normal' lives HIV disrupts many of their taken-for-granted assumptions about their future. Biographical disruption includes disruption of potential future identities, such as being a mother or father. Whilst some young people find strategies to help manage these potential losses others find it more difficult to adjust to a life that excludes parenthood. The fear of death and living with the uncertainty of HIV is difficult and distressing for many young people. As the disease process extends to affect more aspects of life HIV becomes harder to ignore and participants find that they are forced to consider the 'big' issues in life, such as death. Most participants try and limit the effects HIV has on their lives and work hard to find a way to make sense of it. Gaining some control over a future with HIV is essential for young people in order to live as full lives as their condition allows.

7.8. Summary

Having HIV shatters the taken-for-granted assumptions that young people may have about their future, and the world more generally. Ascribing meaning to their lives after they have been told or found out they have HIV is an important, but difficult process for young people. How they make sense is influenced by others around them and their own resources. Most participants report that HIV demands a dramatic re-think about the big issues in life, such as their own mortality. Being young is often accompanied by the assumption of a future life with good health and

a belief that anything and everything is possible. HIV challenges this basic assumption and participants are required to re-think how having HIV may change their life. Some participants see HIV as a punishment, others as a blessing or an opportunity, and for some it is a catalyst for growth and self discovery. Making sense of HIV includes for most participants the realisation that their life span is likely to be limited by HIV and their accounts reflect this.

Some young people find their religious beliefs and /or faith helps them make sense of having HIV. Others rationalise HIV as 'not the worst thing in the world' and compare their situations with others they perceive to be worse off than themselves. Some participants find meaning for HIV in making a difference. Others find HIV changes their 'world-view'. Many young people also recall incomplete narratives about their past and suggest that knowing their HIV story would help make more sense of the illness. Some participants found parents and adults reluctant to talk about how they were infected. Where a parent(s) had died, access to this lost narrative may help young people make better sense of having HIV. Participants' hopes for their future are focused primarily around family, work and relationships, but they also recognise that HIV may thwart the fulfilment of these hopes. The "normal" things in life, such as having children are made more difficult by HIV and for some parenthood is not possible.

Making sense of HIV is a dynamic and changing process and life events and the passage of time impact on how each young person makes sense of the experience. HIV does not dominate all aspects of their lives; young people struggle to limit the consequences on their day to day lives and creatively utilise resources to enable them to maintain a positive identity (Bury 1982).

Chapter 8

Discussion

8.1. Introduction

This thesis extends Bury's concept of 'biographical disruption' (1982) by applying the concept to young people born with a long-term health condition. It explores issues of changing identity and experiences of stigma by young people with perinatally acquired HIV. Biographical disruption is an appropriate theoretical tool because it views chronic illness as a process and as such is useful for furthering our understanding of young peoples' experiences of living with HIV. Throughout the HIV journey young people experience specific incidents which affect the nature of the biographical disruption, hence the thesis utilises a related theory – 'critical moments' (Thomson et al 2002). This concept of 'critical moments' (Thomson et al. 2002), builds on Giddens' theory of 'fateful moments' and helps us understand the ramifications of the fact that the trajectory of HIV is not linear; it is interspersed with 'critical moments' that serve to remind young people of their condition and difference from others. The data from this study explains how this happens and how young people respond. Using the theories of 'biographical disruption' and 'critical moments', the impact of HIV on young peoples' lives may be understood and enable the appropriate support and intervention to be provided for this group.

Thomson and colleagues use the term 'critical moments' to describe a significant biographical moment in a young person's life that has consequences, the significance of which can sometimes only be known retrospectively (2002). These 'critical moments' are unique to each person as no two individuals will respond to the same set of circumstances in the same way or have the same set of personal, social and economic

resources available to them. This inequity of resources influences young peoples' responses and the choices open to them (Thomson et al. 2002:335). As well as 'privileging individual identity and subjectivity' (Holland and Thomson 2009:453) the concept of 'critical moments provides a link between the theoretical understanding of fateful moments and empirical accounts' (Thomson et al. 2002:351).

The chapter begins by considering how a diagnosis of HIV disrupts biography and why it may be experienced differently by young people and adults. The next section considers the theoretical concept of 'critical moments' (Thomson et al. 2002) and explores those identified from young peoples' narratives (Holland and Thomson 2009). The final section looks at how the responses of young people to disruption are shaped and influenced and the choices they make.

8.2. Biographical disruption and young people with HIV

Chronic illness, according to Bury (1982), disrupts the structures of a person's everyday life; their sense of continuity, autonomy, control and meaning. Three aspects of this disruption are considered here: firstly the 'taken-for-granted assumptions and behaviours'; secondly, the disruption to an individual's explanatory system resulting in a fundamental re-thinking of a person's biography and self concept; thirdly, the practical response to the disruption and the 'mobilization of resources in the face of an altered situation' (Bury 1982:169). The disruption of chronic illness also includes having to contemplate 'pain and suffering, possibly even death, which are normally seen as distant possibilities or the plight of others' (ibid).

Biographical disruption has mostly been used to interpret the experience of adults with a range of chronic illnesses, including HIV (Carricaburu and Pierret 1995; Ciambrone 2001; Wilson 2007). This concept is relevant to this study as it considers the long term impact of health conditions on biography. It is also useful because it identifies the continuous nature of disruption and emphasising that this is a process rather than an

event. This may be particularly relevant to how young people experience HIV as the disruption created extends beyond the physical effects of the condition. The young people in this study live chaotic and continually disruptive lives.

Although young people are characterised in part by their youth, age is only one aspect of difference that explains why young people are likely to experience disruption differently to adults. Following Bury, Grinyer (2007) observed that the experiences of young people with cancer were different to those of adults. She comments:

Whilst recognizing the potential devastating effect of cancer at any age, the research findings suggest a distinct effect in adolescence and young adulthood resulting from a disrupted biography at a critical transitional moment in the life trajectory. (2007:265)

The impact of chronic illness - on a young person - is particularly significant because it occurs at a key developmental stage. Like cancer, a diagnosis of HIV in any age group presents profound challenges and is distressing. However, Grinyer (2007) suggests that the developmental stage influences the experience. She observes that having a life limiting condition as a young person can disrupt a developing biography 'in its tracks' (2007:265). Similarly, in this study young people found a diagnosis of HIV deeply distressing and it disrupted their biography at a time when they thought their life and future were bright. For example one young person said – 'suddenly you are faced with having to think about the big things in life that you shouldn't have to as a young person, life should just be good and suddenly it all changes' (Charlotte).

The adult experience of HIV is different to that of a young person born with HIV as adults have different health experiences and a longer life span. Many have already established careers and relationships, are more likely to be living independently and be financially secure (Carricaburu and Pierret 1995; Ciambone 2001; Wilson 2007). Young people in this study differentiated between those born with HIV to those who acquire it in

adulthood. The experience was seen as different; for example young people felt adults already had an opportunity to be young and carefree without the worry of being ill or having to deal with the possibility of a premature death. Adults were seen to have enjoyed their youth whereas young people in the study saw HIV as interrupting and spoiling their youth, preventing them from being able to enjoy being young.

Grinyer (2007) suggests that the experience of chronic illness is more disruptive for young people as they are in the transition to adulthood, a time characterised by physical and emotional change (Melvin 2007). Young people are in a less powerful or less secure a position than adults; they are still financially and practically dependent on others for their support and care as they are not yet fully independent. Their dependency creates a different dynamic for the young person in their experience of HIV than an adult. In this study young people looked to their parents for support and emotional security particularly at times of uncertainty.

Young people have limited independence and autonomy and how able they are to make independent decisions and assess risk is open to question. As Thomson and colleagues (2002) observe, they are subject to other people's decisions and 'already living through the consequences of the decisions, or lack of decisions, of others' (2002:338). In this study this is particularly evident in the disclosure process when young people are told their diagnosis, the consequences with which they have to live.

Unlike young people, those diagnosed with HIV as adults will have already formulated a foundation of values, beliefs and identity (in their transition to adulthood). In this study young people articulated how they were still in the process of developing their identity. For example, some expressed how they liked being young as they were not responsible for anyone else and they could still become and do anything they wished. Wilson found that HIV positive mothers 'placed greater emphasis on their pre-existing identity, motherhood, in presenting their lives with HIV infection' (2007:611). Similarly,

Carricaburu and Pierret's (1995) study of HIV positive gay and haemophiliac men noted that previously established identities, such as being gay or a haemophiliac, became stronger and reinforced after diagnosis. They termed this process 'biographical reinforcement'. Thus having a strongly established previous identity enables individuals to more easily distance a new and stigmatised dimension to their identity; which may lessen the impact of disruption. Although prior to their diagnosis the young people in this study had pre-existing identities such as being friends, siblings, daughters or sons, unlike adults they had not all yet acquired additional roles, responsibilities or identities that may come with age, thus previous identities may not be sufficiently developed or robust enough to offset the impact of disruption or distance of an HIV identity.

Previous disruption

The disruption to biography, it has been argued, is less where lives have not been previously disrupted (Ciambrone 2001; Faircloth 2004; Harris 2009; Pound et al. 1998; Williams 2000). However in this study, most young people born with HIV already had disrupted lives. For example, young people experienced 'critical moments' of moving country, moving house, the death and illness of parents and siblings, changing schools, caring for family members, all of which contribute to the creation of a disrupted environment.

Bury (1982) and others observe that the context of an individual's life affects how chronic illness is experienced and the disruption it brings (Carricaburu and Pierret 1995; Pound et al. 1998; Faircloth 2004; Whetten 2008; Williams 2000). One of the criticisms of Bury's (1982) concept is that it assumes a life free from previous disruption and is therefore not applicable to people with an already disrupted life (Ciambrone 2001; Faircloth 2004; Harris 2009; Pound et al. 1998; Williams 2000). The degree of previous disruption for individuals is relative and subjective therefore it is difficult to make direct comparisons. In this study the young people experienced HIV on top of already complex lives, which for many include migration and bereavement.

Over forty per cent of young people in this study arrived in the UK as refugees or asylum seekers with some living in temporary accommodation for several years and having to cope with all the associated disruption. Another common disruptive experience is bereavement; the majority of interviewees had experienced multiple bereavements with over seventy per cent having lost one or both parents. Such loss creates major changes and upheaval in family life as the principle carer may have died or become ill thus leading to the need for alternative care arrangements such as being raised by grandparents or other extended family members.

Additionally young people experienced disruption as a result of parental drug use, trauma and separation from families. This is similar to the disruptive experiences described in Ciambrone (2001) and Harris's (2009:10) studies. Ciambrone observed that women diagnosed with HIV who had experienced domestic violence, trauma, drug use and separation from their children, found the disruption of HIV to be relative (2001:517). These studies suggest that a previously unsettled life may lessen the impact of any subsequent disruption however in this study a diagnosis of HIV was a major 'critical moment' that redefined these young peoples' lives.

The disruption of taken for granted assumptions and behaviour

The next section considers aspects of Bury's biographical disruption; the first being 'disruption of taken for granted assumptions and behaviour'. This concept is applicable to a range of different long-term conditions (Bury 1982), but the knowledge of an HIV diagnosis disrupts particular assumptions. For example it challenges the belief that young people are 'well' - particularly for those who previously had no major symptoms nor recurrent illness. Some young people in this study, who were asymptomatic, assumed they were healthy until told they were HIV positive. Other participants assumed they had 'something wrong' but did not know it was HIV. This study shows how everyday taken for granted behaviour is affected after diagnosis. Relationships are re-evaluated in light of this new information and young people believe they change. For example, after

diagnosis they do not feel as free to talk to friends and family they fear social occasions and do not feel free to develop sexual relationships. The assumption that they will have sex, particularly unprotected sex is questioned in light of HIV. One participant reflected how his assumed sexual freedom, being able to have a 'one night stand' or 'sleep around' having several sexual partners without thought, was no longer an easy option. When another young man's girlfriend accused him of having an affair, he thought 'if only I could' - he believed HIV now made it too difficult. These examples illustrate how assumed patterns of behaviour are challenged by such 'critical moments'.

HIV also challenges the normal assumption of a long life and introduces the possibility of a premature death. This 'awakening to death' (Charmaz 1997:39) represents a critical moment. In this study young people said that the moment they realised that they had HIV the fear of death was never far away from their thoughts. This preoccupation with death challenges the assumption of the natural order of life; that is that older people should die before the young. This was seen by young people in the study as being inherently 'unfair' and led to a questioning of their idea of 'natural justice'. This study shows how the fear of death is re-visited over time as new symptoms appear or illnesses become more common as the disease progresses, a fear that is common in conditions other than HIV, such as cancer and leukaemia (Bluebond-Langner 1989; Grinyer 2001) and is reinforced as health deteriorates. As with other long-term conditions, young people in this study, following their diagnosis, commonly reflect on and review their life (Grinyer 2001; Bluebond-Langner 1989).

Disruption of biography

HIV can be seen to disrupt a young person's past biography in that previously 'taken for granted' assumptions about their personal and family history are brought into question. In this study 'critical' moments include instances where young people realise that family members died from HIV rather than from cancer as they had previously been told. It also demonstrates how young people re-assess and try and make sense of half truths as they

re-construct their past. Up until this point they have been shielded by what I call a 'protected biography' being unaware of their HIV status. Parents have kept them within what Goffman (1963:46) describes as a 'protective capsule'. This protective biography is maintained over time by stories and explanations constructed to cover events connected to HIV such as explaining hospital admissions or why they had to take medication.

As well as disrupting the past, HIV disrupts the present and the hope of a 'normal' biography. The idea of a 'normal' biography, according to du Bois-Reymond (1998), is a 'traditional' one where an individual leaves school, trains for a job, gets married and has a family. Young people do not all follow this pattern but there remains an assumption that this is 'normal'. In this study the 'normal' biography is called into question as young people fear not being able to marry, have children or fear being less desirable to potential partners. They also fear that their life may be limited by HIV and that they may die before they are able to experience what they consider to be the 'normal parts of life'. With HIV every change challenges their perceptions of a normal biography.

The possibility or assumption of what Beck (1992) refers to as a 'choice biography' (Beck 1992; Beck-Gernsheim 1996; Brannen and Nilsen 2002; du Bois-Reymond 1998) is also changed and replaced by one I call a 'restrictive biography', where the choices available to young people are limited. The notion of a 'choice biography' described by Beck (1992) and developed by others (du Bois-Reymond et al. 1991; Thomson et al 2002) is based on the idea that modern 'western' societies provide more options for young people to choose from. Young people are expected to reflect on these options and justify their decisions and choices. Some may not feel able to make a 'good' choice or feel restricted from making a certain choice and it is this 'tension between option/freedom and legitimation/coercion which defines 'choice biographies' (du Bois-Reymond 1998:65).

In this study the idea of choice is limited by a diagnosis of HIV; young people believed that certain choices are no longer possible or likely to be made more difficult. The

realisation of this is a 'critical moment' for young people as they see that the freedom to choose any direction in life is denied. Whilst their peers pursue, or talk of pursuing exciting options, the young people in this study expressed feelings of sadness and disappointment as they believed their future not to be as bright as that of their peers. In a youth culture that privileges agency and the freedom to choose the limits and disruption to choice that HIV brings presents particular difficulties for young people (Brannen and Nilsen 2002). Youth is defined as a time of experimentation and spontaneity (McLeod 2002): for example in this study one young person reflected: 'I can't even experiment with drugs like others do as you risk messing up your medication' (Elijah). For these young people the common experiences that define youth are limited or are made more difficult and the consequences more dangerous.

Young people have to respond to the 'critical moments' (Thomson et al 2002) that the trajectory of HIV presents and this may require continual adaptation; the young person may have to adapt 'the project of self' (Giddens 1991) as their biography takes a turn in an unplanned or unanticipated direction. This study shows that HIV disrupts life trajectory in a range of ways that young people have to respond to, such as receiving information about deterioration in their health. Examples include: being told they have to start or change anti retro-viral medication as the immune system deteriorates; being rejected for a lung transplant when diagnosed with pulmonary hypertension. These represent 'critical moments' for individuals when they have to respond and adapt to a new situation and find a way to carry on. Biographical disruption is a process where young people have to continually reassess, readjust, respond in an appropriate way, normalise and then repeat the process over and over again. Their changing circumstances means that 'the project of self' has to be re-considered or given up and a new one created (Giddens 1991). The trajectory of HIV is characterised by such disruption and loss and this includes the loss of a planned 'self' and a planned future.

8.3 Re-thinking biography and identity

HIV is not unique in bringing unpredictability and introducing uncertainty into an individual's life; there are many life-limiting or long-term conditions, such as cancer, cystic fibrosis, or leukaemia whose diagnosis bring both uncertainty and unpredictability (Bluebond-Langner 1989; Grinyer 2001). Most undermine a young person's ability to give direction to their future biography and results in a reluctance to make plans for the future (Grinyer 2001).

The future where anything was possible is replaced by one that is controlled by the demands and the progress of the disease. In this study young people adjusted to the disruption of HIV by organising their future biographies around their condition and the restrictions associated with it, for example, several young people wanted to travel while they were well and participate in active pursuits whilst they were mindful that this might not always be so. This is a practical way of dealing with the situation and managing the effects of HIV. Having to re-think biography in the light of HIV means that young people face the potential loss of future roles and identities such as being a parent or partner, and this has implications for their current and future view of self. In this study young people anticipate future 'critical moments' and try to counter them by pursuing dreams whilst they can. For example, a young person wanted to go to Africa to fulfil her aunt's legacy by setting up a home for children with HIV. Another illustration of how young people fear and anticipate future 'critical moments', is having to tell a sexual partner; young men said they delay and avoid sexual relationships in order to prevent this situation. HIV challenges physical, emotional as well as social taken for granted assumptions and behaviour. Past assumptions about a hoped for future are thrown into question as young people engage in 'a fundamental re-thinking of biography and self-concept' (Bury 1982:169).

In her studies on how chronic illness affects identity, Charmaz (1997; 1995) supports the suggestion that a long-term illness requires identity to be reconsidered. She observes that moving from a view of self as 'healthy' to one that is 'sick' affects identity (Charmaz

1995). As Williams (2000) observed, Bury's (1982) concept of 'biographical disruption' excludes those individuals who have genetic health conditions or who acquire them from birth, such as perinatally acquired HIV or cystic fibrosis. These individuals have to adjust to the idea that they have actually had a 'sick' identity all their lives. Chronic illness has a considerable impact on a person's identity (Charmaz 1983; 1995) and can change a person's self-perspective. How much disruption HIV brings to a young person's biography may be influenced by how they see themselves in relation to their condition. Bury (1982) noted that different conditions carry with them symbolic meanings which vary considerably, and affect how individuals view themselves and how they think other people see them. A diagnosis of HIV introduces a new dimension to identity that has a particular stigma attached to it.

In this study young people found the stigma attached to HIV to be a major problem. The stigma of HIV influences all relationships and affects how young people anticipate they will be treated by friends, family and the wider community. It creates 'critical moments' (Thomson et al. 2002) when young people have to manage exposing a stigmatised identity. It also shows how they see themselves and their new identity. For example, a young woman reported how she joined in with her school friends talking in a derogatory manner about people with HIV in order to avoid suspicion or risk of being asked awkward questions. Being seen as sympathetic or too understanding about HIV was to risk exposure.

The stigma of HIV leads young people to re-construct their new identity whilst keeping HIV concealed. The negative associations of HIV were mentioned by all participants and influenced their view of self. For example, one young person said 'if HIV is viewed as 'bad' does that make me bad?' Feelings of being an 'outcast' and knowing they carry an infectious condition that can be passed on serve to reinforce the negative view of self that young people express in this study (Flowers et al. 2006; Chapman 2000). The fear of stigma influences how young people live their daily lives and all subsequent social

interaction. This study shows that young people are always mindful that they must avoid disclosure or arouse suspicion. Examples include, when on a school trip being asked by the teacher in front of friends what the medication is for or being aware not to appear too knowledgeable in class when HIV is discussed. These situations lead to a relentless and continuous pressure of disruption on young people as they have to be forever on their guard. Young people also said that this pressure engendered feelings of powerlessness of being apart from others. The consequences of revealing a stigmatised condition led them to set themselves apart for fear of rejection. This setting apart denies them access to young people's natural support group, their peers.

This study shows how the stigma of HIV influences this new self-perception because even though their illness is not visible to others, some believe it is. For example, one young woman said 'I feel as if I have a big arrow on my head that says I am HIV'. They are 'discreditable' (Goffman 1963) in their own eyes and they anticipate they will be 'discredited' in other people's eyes. Unlike other conditions, developing a new identity that includes HIV is particularly difficult as it is often viewed as the fault of the individual. HIV is linked with sex, shame and 'life style choices' rather than seen as a case of random luck on the 'fate continuum' (Sontag 1990; Weiner 2009; Thomson et al. 2002). Constructing an identity that includes HIV when it is viewed so negatively by the young people themselves leads to a separation of HIV from the main part of their identity. In this study young people said the negative representation of HIV undermines their self esteem and makes it hard for them to find some positive self-worth.

How dominant a health condition is and how much it impinges on everyday life affects an individual's view of themselves (Bury 1982; Charmaz 1997). In this study this can be seen in the way young peoples' self perception changes over the trajectory of their disease. For example, participants describe how living with HIV from birth 'HIV just became part of me' and one said 'HIV and I grew up together, it's always been there'. How central a role HIV plays in a young person's life changes over time and

circumstances; sometimes it assumes a 'master status' identity (Goffman 1968), particularly when ill, other times it does not. From this study HIV appears to be no different in these aspects to many other long-term conditions (Charmaz 1997; Grinyer 2001).

With life limiting conditions characterised by a deterioration in health, such as cystic fibrosis or some cancers, it becomes more difficult to hang on to an unaltered self as the disease progresses (Charmaz 1997; Grinyer 2001). In this study, holding on to an identity that does not include HIV is less difficult for those that remain asymptomatic. Charmaz (1997) found that where individuals are able to maintain their social roles and their health had not been compromised, identity is more likely to stay intact. However, this may be different with progressive and life limiting conditions and in this study individuals eventually need to re-appraise their identity as their health deteriorated, and their condition became harder to ignore. This is a 'critical moment' as a young woman said: 'HIV just keeps taking more of me away' (Emma).

This study shows that as the disease process accelerates and young people are hospitalised more frequently, HIV disrupts more of their biography. It becomes harder to ignore and they are forced to adopt a new identity that includes HIV. As Charmaz (1995; 1997) observes much of an individual's everyday reality and their sense of self is referenced in their past, present and in the future and where a chronic condition, like HIV, disrupts all of these and results in the loss of certain social roles, identity is challenged. She adds: 'Losing valuable attributes, physical functions, social roles, and personal pursuits through illness leads to the loss of their corresponding valued identities' (1995:269). In this study where young people have been unable to fulfil certain roles, it is a critical moment as they realised the impact of being HIV positive. This is due to ill health or disability for some, for example, one young person could not participate in sports at school. Another young person felt unable to contribute to a school drama

about someone with HIV fearing exposing her status illustrating how HIV can remove social roles.

This study shows that developing an HIV identity is a dynamic process; the changes in identity begin, and are reflected in the biographical disruption after diagnosis of HIV such as: the need to conceal an HIV status, take medication or manage social interactions. In this study young people revealed how HIV influences their personal and social interpretations as well as their actions (Tewksbury and McGaughey 1998). HIV becomes part of a young person's identity on both a personal and social level; and the challenge is to find an identity that includes HIV that they see as being of value. Young people in this study did not find one single HIV identity, but rather a range of identities that they constructed, reconstructed and enacted.

8.4. Responses to disruption and mobilisation of resources

In this study young people respond to the disruption of HIV by developing explanatory accounts and narratives. These narratives are not time bound nor experienced singly and participants move between them as circumstances change and the disease progresses. These narratives may reflect family narratives such as a religious justification for having HIV infection for example: 'God gave me HIV for a reason', 'God gives HIV to those he knows have the strength to cope with it' (Amy). Others developed a positive narrative where they found benefits in the disruption of HIV such as: 'HIV has made me stronger', 'HIV has made me more understanding of other people' (Alica). However, these narratives are influenced by the social processes and circumstances of young people's lives and some are more able to draw on positive resources than others. Responses to disruption are then shaped by circumstances but these in turn are influenced by class, gender and race. However, as previously mentioned, they are also shaped by the stigma attached to HIV.

Some young people in this study responded to disruption by undergoing, what Courtenay and colleagues call a 'perspective transformation' (Courtenay et al. 2000). The disruption caused by HIV led some young people to a changed outlook and worldview. HIV heightened their sensitivity to others because through the experience of disruption they developed a greater understanding or empathy of human frailty. For example, young people said how having HIV made them more aware of 'serious stuff in life' and more understanding. Experiencing a stigmatising condition where individuals are often deemed as unworthy of support appears to generate intensified feelings of care and concern for others and thus transformed their perspective. In this study participants developed an acute awareness of others' pain and suffering and learned to empathise and with the situation of others.

Some young people developed altruistic motives as a response to their own experiences of pain and sadness; several participants wanted to help other children in similar situations either as doctors, psychologists, nurses or social workers. These young people wanted their lives to 'count' and for 'something good to come out of having HIV' (Matthew). Others expressed an urgent desire to achieve something of worth in life and to undertake a meaningful role or to be of service to others. For example, one young man wanted to be the doctor that found the vaccine, another wanted to set up an orphanage for children with HIV abandoned by family. This finding is similar to other studies where individuals live with a life limiting condition and express a strong wish to leave something of significance behind (Courtenay et al. 2000; Grinyer 2001).

Taking some control of events may enable young people to manage disruption better. In this study young peoples' main concern is the control of information about diagnosis. Charmaz suggests most of the dilemmas caused by a chronic illness focus on 'control of information, control of identity, control over emotional responses and over one's life' (1982:110). Taking control, in an unpredictable situation, may limit the disruption to

biography. In this study, for example some young people tried to take control of their situation and exercised agency by ruling out marrying or having children. This strategy is developed to avoid future distress and thus their biography cannot be disrupted by infertility. Taking charge of a situation characterised by uncertainty may lessen the feelings of powerlessness.

This study demonstrates that control is maintained by young people after the 'critical moment' of diagnosis by continuing to conceal their status. By keeping HIV a secret part of life it creates distance between the young person and HIV. Charmaz (1982) suggests that an underlying part of concealing illness is not to grant any reality to the illness, but this may not be the case with young people who are HIV positive. As previously discussed, most young people in this study felt that concealing an HIV status was the only realistic option. Concealing a chronic condition enables individuals to continue to function un-stigmatised and participate in all social interaction. To maintain this separation in the long term, it is necessary to control information as well as to control identity (Charmaz 1982). It may also enable young people to minimise 'critical moments' to ones that are in their control.

In this study, young people managed to maintain a separation of identity in both public and private spheres. All individuals have an inner private life but - for this extends to their family. For example, a young woman who shares a bedroom with her twenty-seven year old sister who does not know either her status or her mother's. Other young people spoke of 'two separate worlds, one with HIV one without'. The world with HIV is one in which they inhabit alone. Charmaz suggests that the extent that people keep their illness separate is crucial, as by 'keeping illness separate they allay disquieting feelings about themselves and their bodies' (1982:663). Whilst this response may be an effective control and coping strategy when young, it becomes a more difficult position to sustain or retreat from as individuals move into adulthood. This study found that keeping HIV separate may come at a cost for the young person because over time the stress of

concealment results in increased isolation and loneliness. For example, most young people had not disclosed their HIV status to friends (at the time of interview) and one participant said that the decision to tell long standing friends 'becomes harder the older you get as you then have to explain why you didn't trust them enough to tell them before' (Daniel).

The last aspect of 'biographical disruption' (Bury 1982) considered here is the mobilisation of resources. The practicality of mobilising resources entails locating and generating those resources in the first place and young people may have less well developed resources than adults. Young people in this study looked primarily to family as their main source of support and guidance as one young man said about his family: 'even though we don't talk about it I know they are there if I need them'.

The importance of friends to young people was also revealed in this study and reflects similar findings to that of other studies. Friends are a particularly valuable source of support for young people with chronic illness (Frink Sherman et al. 2000; Kyngas et al. 2001). Studies of young people with cancer and other life threatening conditions highlight how friends are an important source of support (Chesler and Barbarin 1987). This study also reinforces the theory of the importance of peer group for young people (McLeod 2002). Part of being young is the acceptance and approval of peers, being part of a small group; but HIV has the potential to separate them from their peer group. In this study young people fearful of stigma removed themselves from their peer groups and potential support network before they were 'actually' excluded or rejected. This study shows how this pattern of behaviour is one that in some instances is copied from their parents as one young person said 'if it worked for mum then its good enough for me'. Most young people in this study said they would like to tell a friend their status. Not feeling able to share their situation with friends' resulted in increased isolation. On the other hand where young people were open and disclosed their HIV status to friends most found they received support and acceptance.

Mobilising resources for young people can be difficult whatever their health condition. From this study young people found it particularly hard when they are living with a condition that cannot be discussed openly or does not generate sympathy unlike other conditions, such as cancer. As one participant reflects: 'if I had cancer people would be kinder, like sympathetic, and maybe help me more, but with HIV it's not the easiest to talk about and people aren't always kind'. This belief can make it harder for young people to locate and mobilise resources which ultimately results in greater isolation. This study shows that although most young people are incredibly resourceful the experience of living with the disruption of HIV takes its toll and it remains fundamentally a lonely experience.

8.5 'Critical moments' in young peoples' HIV trajectory

Critical moments can be focused on the disease process as well as the 'ordinary' moments in a young person's life. There are some critical moments that are under a young person's control and others that are not. Turning points in biographical accounts have been well researched and developed across youth studies research (Giddens 1991; Henderson et al. 2007; Holland and Thomson 2009) though little has been developed around the idea of 'critical moments' for those with a life limiting condition. The illness trajectory of those born with HIV is generally characterised by recurrent and unpredictable infections and the gradual decline of the immune system. This is accompanied by an on-going process of disruption to biography (Bury 1982), as discussed above. The disease process as well as the disruptive process is characterised by 'critical moments' (Thomson et al. 2002). How young people experience and respond to these moments can significantly alter their choices and their life course and the subsequent management of disruption.

Identifying 'critical moments'

Extracting 'critical moments' from young peoples' interview narratives is problematic because it is distant from the objective circumstances of a young person's life and is based on an interpretation of what constitutes a 'critical moment'. It is also highly dependent on a young person's ability to tell their story and to understand the world and events in their own lives. The quiet young person may have experienced many 'critical moments' but their inability to describe these in the interview setting does not preclude their existence. Thus highlights the tension between 'the life that is lived and the life that is told' (Thomson 2007:77). However, the thematic analysis of the data enabled the dominant themes and 'critical moments' to be identified and the data chapters reflect these.

8.6 Key 'critical moments'

Critical moments in the trajectory of HIV tend to focus on control – the control of information.

Being told

The diagnosis of HIV constitutes a 'critical moment' (Thomson et al 2002) as well as a 'disruptive event' (Bury 1982) and is the actual event where a young person is formally told – the formal telling. This subjective experience of HIV disclosure offers an insight into young peoples' feelings about the event. Their accounts detail where, who and what was told or what they remember hearing. In this study, most young people understood the significance of the event at the time. However some only understood the significance retrospectively (Thomson et al. 2002). This was the case for those told their diagnosis as young children. The 'critical moment' of disclosure was commonly accompanied by disclosure of a parent's status thereby adding another dimension to this experience which may influence a young person's response. The study found that those who already suspected 'something was wrong' also found the moment of disclosure

significant as it ruled out any uncertainty or the possibility that they could have been mistaken.

In this study young people had no control over the actual event or timing of disclosure. This lack of agency is compounded by the discovery that their condition has been concealed from them. Finding out that they have either been deceived or protected from their condition can lead to further to feelings of powerlessness. Thomson and colleagues (2002) describe young peoples' 'critical moments' on a continuum with 'fate' at one end and 'choice' at the other. Death and illness were positioned at the 'fate' end of the continuum as they were seen as beyond an individual's control. Perinatally acquired HIV could be placed between the fate and choice ends of the continuum because there may be someone to blame for passing the infection on. In this study how the young person contracted HIV raises questions of blame and therefore where it is placed on the 'critical moments' continuum is not straightforward. For example, one young person said 'I don't know if I blame my mother, I just wonder why she didn't get tested before I was born'.

What makes a moment critical for a young person?

How and why certain moments are 'critical' focuses on the particular consequences of the moment. As Thomson et al (2002) observe certain 'critical moments' have particular significance for biography and the disclosure of an HIV status fits this category. The formal event of disclosure is one that has complex and far reaching consequences for the young person. As Thomson et al. suggest, such 'critical moments' – can 'provide the momentum to experience change or force the transition to adulthood' (2002:339). Thus the moment of disclosure can force change; in this study the event marked life before and life after knowing and was a major critical moment for young people. The diagnosis of HIV changes a young person's life course and biography – it brings an altered identity and an altered biography and as such is life changing because it is a condition without a cure and one that introduces the possibility of a premature death.

The disclosure of HIV introduces a framework in which young people now have to plan and structure their lives. All subsequent 'critical' moments are placed within this new frame of reference. Although such moments may stand alone as events, their impact extends beyond the event and creates 'biographical disruption' (Bury 1982). This study found that young people make connections with the moment of disclosure and subsequent critical moments. For example: family relationships become more difficult, a parent leaves the family home or decides to live apart with a non-infected sibling are now viewed as direct consequences of the disclosure of HIV. Although in reality disclosure may act merely as a catalyst to some of these events, the young person may view this as a case of cause and effect.

A moment is 'critical' as it alters a person's sense of self and identity as one young person said: 'All those years I had it and I didn't know and then I was told. Suddenly, like overnight, I wasn't the person I thought I was and wasn't the person my friends thought I was, I had been living a lie' (Samuel). How young people respond to these moments may demonstrate what influences their response.

8.7 Responding to 'critical' moments

The ability to respond to 'critical moments' is determined by a range of external as well as internal factors (Holland and Thomson 2009; Thompson et al. 2002). As Bertaux and Thompson observe: 'In choosing a particular course of action, structural constraints such as economic needs interact with value orientations, moral obligation, self-determined goals, and the individuals own perception of the situation and choices ahead' (1997:17). In this study, making the 'right' choice was important to young people but one they found difficult. Each young person lives within a different set of circumstances, their family and social context varies; access to personal, social and economic resources are particular to them. In this study, the young person living alone in a hostel, recently arrived from Zimbabwe, estranged from family, and surviving on basic state benefits has access to fewer resources than one living in their own culture, with two parents/carers in an

affluent home and supportive social environment. Thus these different circumstances can result in a different range of choices available to the young person; one has the support and guidance to help them make choices, the other does not.

Personal as well as economic resources are likely to influence responses. This study shows that some young people are able to use 'critical' moments as a catalyst to personal growth and development. For example, a young person reflects: 'I kind of like the effects HIV has had on me, it has definitely made me more focused and disciplined' (Amy). A 'critical moment' can be used and responded to positively, it can provide an opportunity for change and a different course of action. In this study some young people found it provided structure and direction in their lives. HIV can act as a 'positive force' to generate discipline, establish boundaries and a re-prioritization of life goals that some find helpful. Why some young people use 'critical moments' to provide momentum for change is unclear. This study suggests that young people who demonstrate a 'positive' response may draw on their own personal resources as not all live in supportive environments.

8.8 Influences on responses

There are a variety of influences that affect response including: agency, family, timing of critical moments, and the social context and the role of the expert help. The influence of agency on decisions and choosing a particular course of action is affected by young peoples' circumstances as well as their age. In this study where a young person was living independently he/she displayed more agency than those living under the care and financial support of a parent. Being independent of parents may influence agency. This study found that after the disclosure of diagnosis young people felt more able to act with agency as they had control of the information previously denied them. Macdonald and Marsh (2005) and others (Webster et al. 2004) warn against overplaying the importance of agency, suggesting that it is only one factor that influences choices and it is structural inequalities that are more likely to restrict choice.

In this study young people said the stigma of HIV was a major influence on how they respond. For example, one young person wanted to tell her 'best friend' immediately after diagnosis but felt she could not as in disclosing her own status she would reveal her mother's. One of the unintended consequences of this situation is the undermining of sense of agency. Agency is difficult for a young person with perinatally acquired HIV to exercise, because there are certain expectations around their behaviour to ensure the protection of their own status as well as their mothers. This study found that the HIV positive parent plays an important role for the young person and this can create tensions. For example, a young person described how her mother's response was based on ideas from the 1990's - 'all that tombstone stuff' and she believed she may want to consider other choices other than silence. There may be a need to re-consider and allow this generation of young people greater autonomy in their disclosure decisions; they may choose to make different decisions to those of their parents.

In this study young people described how the ways in which families communicate and deal with 'critical moments' influenced the disclosure of HIV. A family who had lived with the knowledge of HIV before disclosure to a young person they had already established patterns of response. Most families did not feel able to talk openly about HIV. The expectations of an HIV positive parent/carer influenced a young person's response and choices. Young people found the sense of identification and moral obligation difficult to ignore without feeling a sense of betrayal. An HIV positive parent/carer acted as a key role model in an environment where there were few. The study shows that an infected parent offered the only example of how to live with HIV 'successfully' and young people looked primarily to them for guidance.

The timing of 'critical moments' in young peoples' biographies is significant (Brannen and Nilsen 2002; du Bois-Reymond 1998; Thomson et al. 2002) and likely to affect their response. In this study young people said the timing of disclosure is significant and may

influence the response and subsequent disruption. Some young people told at a younger age expressed the belief that they had time to 'grow up with HIV' and HIV had become part of their identity. In contrast those told at an older age found adjusting to the idea of being infected harder as they had grown up without HIV being part of their identity. For example, a young woman told her diagnosis at sixteen felt it was too late and she wished she had been told earlier. She connected her subsequent 'rebellion' with the timing of diagnosis and related this to her school exclusion and pregnancy. Understanding the impact of timing may alert practitioners to 'critical moments' when support and intervention could be offered to young people.

Brannen and Nilsen (2002) suggest that young peoples' time perspective and life course has become increasingly individualized with the process of transition to adulthood extended. This results in a prolonged period of 'youth' and as reflexive agents young people negotiate their own route into adulthood. However, their agency continues to be shaped by structural influences (Roberts et al. 1994). Young people tend to live very much in the present moment (Brannen and Nilsen 2002) of being young and this influences the way they envisage their future and adulthood. In this study some young people described how they wanted 'to live for the moment and do everything' even more so after diagnosis as their life may be time limited.

Young people do plan for their future, and this study found that most make some plans for the future apart from those who had severely compromised health. For example, young people had career plans, aspiration for training, wanted to get a mortgage and look ahead. Similarly, Brannen and Nilsen found that the young people with cancer viewed the future as a positive challenge and something to be 'calculated and controlled' (2002:530). This study found that young people wanted to control any part of their health they could, focusing on keeping well and healthy - to enable future plans to be possible. The diagnosis of a life threatening condition challenges the assumptions of time and life

course and disturbs young peoples' timing; the idea that one can live forever, a feeling young people expressed in this study, is fundamentally questioned.

Like all 'critical moments, HIV is set in an historical as well as social context for young people in the UK. All chronic conditions bring their own degree of stigma and the public discourse around conditions such as cystic fibrosis, epilepsy or cancer incorporate stigmatising and negative elements (Sontag 1990; Grinyer 2004). The character of the discourse around HIV brings particular problems for young people as it is one that is highly stigmatising and morally judgemental, (Sontag 1990; Weiner 2009).

In this study young people found the stigmatising nature of HIV a major difficulty and feared being socially excluded if people discovered their status. The fear of rejection or discrimination influenced their responses and behaviour. Young people said they did not want to be linked to a sexually stigmatising condition. They believed their choices were shaped and influenced by how HIV was represented in the media and social talk. This study found that the negative association is also gendered. Young men feared being labelled 'gay' whilst young women feared being labelled 'promiscuous'. Young peoples' responses were always considered with other people's reactions in mind.

Individuals consult 'expert help' to inform their response and help them decide the best course of action and as a result they develop new skills that empower them (Giddens 1991). In this study young people with HIV said they rarely sought 'expert help'; however, at the time of disclosure they received 'advice' from the disclosing doctor and parent(s). Young people gathered expertise over time by observing and listening and the 'expert help' gathered informed their decision to conceal their status. The expert help from an infected parent was highly valued because the infected parent may be the only other infected person known to the individual.

As Thomson et al. observe, young people are in a position of dependency and as they have limited autonomy are particularly vulnerable to the decisions of others (2002).

The expectation that seeking 'expert help' will be empowering assumes that the individual will develop a new set of skills but for the young person with HIV this may not be the case (Giddens 1991). In this study 'expert help' serves to highlight the serious and dangerous nature of HIV and the potential pitfalls and disaster of making the wrong choices. The 'expert help' advocates only one choice which is not to tell. This results in feelings of powerlessness and re-emphasises the young person's lack of agency, rather than being empowering. The findings from this study suggest that 'expert help' for young people can serve to control the decisions they make and restrict the choices they feel are open to them; but in this study the infected parent was the most powerful source of guidance, and this made independent decisions harder for this group of young people.

8.9 The silent response

There is no evidence in this study that young people's response to being told they had HIV was based on their assessment of risk (Giddens 1991). They maintained that at the time they had no choice - indeed in some situations there may only be one choice which is to keep quiet and not talk to anyone about HIV. The advice derived from the opinion of experts and significant others and proved to be effective as it avoided some of the immediate difficulties HIV presents. It is understandable therefore why most young people in this study initially choose to continue to conceal their HIV status as to do otherwise was to embark on a high risk strategy. Silence has considerable consequences, but is seen as the 'best' choice in a 'bad' situation as it offers protection and it keeps the young person safe from potential stigmatisation and discrimination. Young people follow an established and apparently successful pattern of disclosure within the family. However, in this situation young people saw themselves as powerless believing they had no choice.

This study demonstrates how young people work hard to keep their HIV status concealed from family and friends. This changes relationships as they have to be continually on their guard to ensure their secret is kept. However, choices are not fixed and over time as young people consider their decision and their circumstances change; some make different choices as they move into adulthood. The following section considers the second 'critical' moment: when a young person decides to tell another person their HIV status. Whilst the previous event of being given the diagnosis was controlled by others, (or the person giving the information); when intentionally disclosing their status to others they are in control.

Telling others

The 'critical moments' in young peoples' narratives centre around the decision to tell someone of their HIV status: a friend, sibling or more commonly a sexual partner. This event differs greatly from the previous 'critical moment' as the young person now, acting with agency chooses who, how and how much to reveal, the timing and the place. The decision to disclose an HIV status to another person without any guarantee of their discretion poses considerable risks.

Giddens (1991) highlights the importance of assessing risk when deciding the appropriate course of action or what decision to make in a particular situation; the choice of who to tell involves judging an individual's likely response. Young people in this study described engineering situations with friends where they 'test' attitudes by talking about related topics to discover if those individuals are safe to tell. They describe weighing up the pros and cons of telling to judge if the benefits outweighed the risks and planning a strategy for managing a distressing or angry response particularly when considering telling a potential or existing sexual partner.

What may superficially appear opportunistic is often privately rehearsed. Young people's patterns of telling are influenced by both the social, personal and family

contexts. In this study where HIV is openly discussed from a young age there is greater confidence to tell. In families where this was not the case young people lacked the confidence and are fearful of telling others. There are rare 'deviant cases' (Silverman 1992) where individuals exercise particular agency and go against their family wishes and tell friends and partners. Most of this group were female and were told their status at an older age; had close and established friendship networks and were generally less connected to their families. Therefore the stage of a young person's development may in some cases influence decisions about disclosure.

Responses to the critical moment of telling others

One of the findings of this study is that the experience of telling was a positive one where the response was supportive and accepting. Deciding to disclose an HIV status was accompanied by a set of expectations. This included a sympathetic response; respect for confidentiality and a hope the relationship would survive. In this study where the young person received this response it was an empowering experience. When a negative response was forthcoming feelings of powerlessness re-emerged as well as the fear of potential repercussions of having lost control of their 'dangerous secret' (Claflin and Barbarin 1991).

Where a friend or sexual partner breaches the confidence the young person regrets having made the decision to tell. Losing control over the information can further disrupt a young person's biography. This is accompanied by anger and fear of the possible consequences. This study shows where confidence is respected and acceptance and support is offered, young people feel relieved and empowered by the experience.

A positive experience of disclosure can counterbalance a negative previous disclosure which can result in a more positive view of self. However, if a young person is verbally abused or rejected, they feel powerless and their future ability to assess risk and make the 'right' choice is undermined. This situation also serves to reinforce the previously

held view that telling is dangerous; it serves to re-enforce a stigmatised identity and feelings of shame and rejection which are likely to influence a young person's subsequent decisions.

Thomson et al. (2002) suggest that certain 'critical moments' carry greater consequences than others. HIV disclosure whether being told or telling, sets in motion a whole chain or series of other 'critical' events that impact on a young person's life course. These do not necessarily centre exclusively on HIV. Although HIV impacts on many of the ordinary biographical events of youth, it does not always dominate the transition to adulthood. In this study young people experience other 'critical moments' that are not directly linked to HIV such as moving house, moving school, starting college and making friends, but these are made more complex by HIV. The 'critical moments' in an HIV trajectory are likely to be similar to any other life threatening conditions such as moving away from the treatment centre; however, the stigma of HIV is particular. This study shows how consequential 'critical moments' are, depends on the individual's response and the choices they make; this in turn is influenced by an individual's circumstances and the personal and social resources available to them.

Summary

Bury's concept of 'biographical disruption' and the idea of 'critical moments' (Thomson et al. 2002) are used in this thesis to explain the impact of HIV on young peoples' lives. Biographical disruption is a useful concept and relevant to this study in that it explains how the disruption of long-term conditions is a process that is not linear or static. It is a dynamic process that is interspersed by 'critical moments' (Thomson et al. 2002) that serve to remind young people of their difference and their condition. This thesis extends Bury's concept, as suggested by Williams (2000), by relating it to young people born with a life limiting condition. Applying these theoretical concepts helps explain how HIV creates disruption in young peoples' biographies and the part 'critical moments' play.

The three aspects of Bury's (1982) concept considered in this thesis are the disruption of taken for granted assumptions and behaviour, a re-thinking of biography and identity, and the need to mobilise resources to respond to an altered situation. Young people are forced by the 'critical moments' HIV creates to continually adjust and accommodate HIV and make sense of being HIV positive. How young people respond to the disruption to their biography and critical moments that occur in their lives is influenced by a range of internal and external factors. Their youth, characterised by a lack of agency, autonomy and dependency affects their responses. When a young person's transition to adulthood is disrupted by the diagnosis of a stigmatising and infectious health condition, there are major implications.

HIV has particular characteristics and is accompanied by stigma and a moralising discourse. It disrupts a young person's past biography because it challenges previously held assumptions about the past. A formal diagnosis of HIV uncovers the 'protected biography' that has been given to young people and reveals unknown truths about their past. It disrupts a present biography by challenging the possibility of a 'normal' or 'choice' biography which is replaced by a 'restrictive biography' where the prospect of marriage or parenthood may be threatened. It disrupts a future biography as young people adjust to the loss of future identities and hoped for biographies. Finding an identity that encompasses a stigmatised and 'discreditable' (Goffman 1963) condition is difficult and in this study young people struggled to find a positive view of self that included HIV. The consequences of revealing a stigmatised identity leads young people to set themselves apart for fear of rejection. By setting themselves apart they are denied access to the support that a peer group could normally provide.

'Critical moments' (Thomson et al. 2002) play a pivotal role in the process of 'biographical disruption' (Bury 1982) as they act as a major interruption and create further disruption which has to be assimilated into an already disrupted life course. This process repeats itself as young people have to continually reassess, readjust and

respond in an appropriate way. The concepts of 'critical moments' (Thomson et al. 2002) enhance the notion of biographical disruption by highlighting key events that extend disruption through a young person's life that may challenge their existing response to disruption. Key 'critical moments' identified from young peoples' narratives focus on the control of information about their condition and include the experience of being told a diagnosis as well as telling someone else.

The unpredictability and uncontrollability of life limiting conditions are evident in the 'critical moments' that occur in these young peoples' lives. By analysing 'critical moments' and how and why young people respond in particular ways, the influences on their decision-making are clearer. Young peoples' ability to respond to such moments may be limited by their previous experience of disruption as well as structural influences; responses are also restricted by the historically stigmatising discourse that has developed around HIV.

Understanding the particular character of the disruption HIV brings as a continuous process within which 'critical moments' (Thomson et al. 2002) occur as part of the ongoing process of disruption may facilitate a better understanding of the overwhelming impact the diagnosis of HIV or other life limiting conditions can have on a young person's life. If 'critical moments' can be identified, or anticipated practitioners and service providers may be enabled to develop more targeted and appropriate services that can be more responsive to these young peoples' needs.

Chapter 9

Conclusions and Reflections

This chapter reflects on the study, considering the methodological implications and theoretical contributions made therein. Drawing on findings from the previous chapters, this chapter considers what young people's experience of living with HIV has contributed to an understanding of biographical disruption, critical moments, stigma and identity and assesses the implications the findings of this study have for young people living with HIV. Areas for future research are suggested.

9.1. Reflections on Methodology

This study set out to explore how perinatally infected young people in the United Kingdom experience living with HIV and the effects on their biography. Part of the motivation was to document the practical, social, emotional and psychological impact of HIV on young people as little evidence existed hitherto. The secondary objective was to document and critically analyse how HIV disrupts biography, thus the study positioned young people as active meaning-makers. The objectives of the research were met in that young people told their previously untold stories and shared their views and experiences through in-depth semi structured interviews. Thus young peoples' stories were heard directly from them which provided unique insights into their lived experience.

Although several other research methods were considered, individual interviews worked well because they provided the privacy and individual focus that this sensitive topic

required. The flexible and informal approach to interviewing (Rubin and Rubin 2005) was appropriate in that it provided some structure through asking questions and allowed probing, but also provided the opportunity for young people to tell their own story in their own way. Undertaking research with young people brings its own challenges and this, combined with the sensitive nature of HIV, meant that much thought had to be given to the design of the study. Adaptability and good humour also proved essential components in interviewing young people because not everything always goes to plan. This study involved having to manage interviews that contained elements of intense emotion.

Basing this study within a clinical environment brought its challenges; for example, the role of the doctor and clinical nurse in selecting suitable potential participants. However, it permitted a wide range of participants to be accessed and a broad range of experiences to be recorded. On reflection, one of the main challenges of the research process was convincing the clinical gatekeepers, the doctors and the NHS Ethics Committee, to consent to the idea of a qualitative study. Being flexible and well prepared covering all aspects of ethical concern helped, but it was also necessary to convince those who functioned primarily within a medical model of the value of qualitative research.

The support arising from my existing professional relationships and reputation were important in gaining access. However, this also created tensions as being viewed as both an 'insider' and at the same time an 'outsider' who may criticise practice was a challenge to the professional caring for the young people. In reality, my prior knowledge of HIV proved to be extremely helpful and marked the beginning of my journey from being a practitioner to becoming a researcher. Consistent reflexivity throughout the research process provided not only an important source of insights but also helped manage the challenges encountered in this transition.

In the process of data analysis, when the store of previous knowledge and assumptions needed to be put aside, a heightened level of awareness made it possible to be open to the themes the data revealed rather than what was anticipated. The difficulty in disclosure

decisions was anticipated as was the finding that most young people did not have anyone to talk to; however the extent of silence and their degree of isolation was unexpected. The extreme experience some young people had of stigmatisation of HIV by peers was a surprise whilst the positive responses from other friends and sexual partners were encouraging. Thematic analysis was effective in highlighting overarching themes and enabling a large amount of data to be analysed. The decision to use a computer software package enabled any assumptions from the data to be questioned as the interview transcripts were analysed line by line. On reflection, my previous experience was a great help in understanding and probing some of the issues young people raised and my prior knowledge of HIV meant that the young people did not have to explain some taken-for-granted issues. For example, this included knowing about the time when there was limited treatment for children available and many children died, or the difficulties medication can pose, such as tasting awful or very large tablets. This small but significant 'insider's' knowledge helped establish rapport and trust with the interviewees and thus facilitated shared understanding that aided the interview process.

The sample size of the study was larger than originally planned. However, this was a unique opportunity to interview 'hard to access' young people. On reflection it may have been useful to interview the young people more than once because the single interviews opened only a small window on the experiences of this group. Nevertheless, the interviews produced a large amount of data, provided a rich source of information and offered valuable insights into an under-researched group.

The data collected was obviously influenced by my positioning as a middle-aged white female which inevitably affected what young people chose to share during the interview process. Given the diverse ethnic mix of the participants one may have anticipated more overt comment on issues of race and HIV than occurred in the interviews. However, several white UK born participants spoke about their perceived stereotypical association with HIV and Africa, and one participant from Uganda and another from Zambia described

issues overtly pertaining to race. For example, one spoke about how her white friends were more informed and open about HIV than her 'black friends' who thought HIV was cured by having sex with a virgin. She saw this as a commonly held view held by her friends, but a view that was originated from Uganda. Elijah also made reference to the perceptions of the black community towards people with HIV and the association with homosexuality was of concern to him in relation to disclosing his HIV status.

Inevitably there are some limitations to the study: in particular the size of the sample. Although the population of young people perinatally infected with HIV in the UK is not large (951 young people over the age of 10 in the UK) the sample size in this study was relatively small to permit generalising the findings to the wider HIV positive population. However, it was large enough in relation to the numbers of young people over the age of 15 who are perinatally infected to identify issues of concern.

A further restriction was the age of participants. The original plan to recruit young people from the age of 13 was not possible because there were insufficient numbers that met the selection criteria. Relatively few young people in this age group had known their HIV status for over a year. The participants were therefore aged between 15 and 24 and provided a rich source of data; most had known their status for several years which it may be argued is sufficiently long enough to given them the confidence to reflect on and come to terms with their situation.

9.2. Reflections on the Contributions of the Study

This thesis demonstrates the value of directly investigating the experiences of those with a stigmatising condition. It highlights the richness and complexity of findings emerging from in-depth semi-structured individual interviews. This study is the first to explore the experiences of young people with perinatally acquired HIV in the UK and as such

contributes to the international debate on the effects of growing up with HIV (Fielden et al. 2006). In the following sections, two areas of contribution are noted.

Empirical Contributions

As an in-depth study of young people's experiences of living with HIV this thesis makes a substantial contribution to understanding what living with HIV is like for young people born with it. Drawing solely from the direct stories of these young people the study presents a view from the young person's perspective. The emerging themes are grounded in participants' personal experiences, values and beliefs. They are accessed through detailed explorations of the experiences of stigma and the effects of HIV upon personal and social identity. Participants' concepts of the stigmatising nature of HIV and its effects on their everyday life sheds light on how 'felt stigma' is experienced and feared by young people. At the same time, different strategies of managing stigma emerge.

How young people experience and reflect on the disclosure process has received little academic attention to date and has focused on when is the right time to tell? or how to tell? (DeMatteo et al. 2002; Feldman 2003; Flanagan-Klygis et al. 2001; Weiner et al. 2007b). This study provides important insights into how the disclosure process is experienced by young people.

Examples of how young people manage and/or fear social interaction provide significant information for professionals working with this group. There is considerable data concerning the impact of HIV upon a young person's emotional and mental health. The detailed picture that participants give of the stress and emotional demands of living with HIV reveals the increased vulnerability of this group to potential mental health problems. The exploration of young people's experiences advocates a reassessment of current and/or previous practice, particularly in relation to disclosure, to be considered in light of this study. In this study some young people said they would like to tell a friend and as other studies have found (Ferris et al 2007; Frink- Sherman et al. 2000; Smith et al. 2008) this may be helpful. The levels of reported disclosure to friends in this study (25% to

friends and 7% told a teacher) is different in comparison with a similar study in Canada (Fernet et al. 2007) which found over 75% of young people reported telling a friend and teachers.

This thesis offers insights into how the disclosure process is remembered and experienced; it also reveals what young people say they knew prior to disclosure. Although HIV is primarily defined as a health condition it emerged from the data that the social implications of the disease ultimately characterise and define it for these young people. They found the stigma and social aspects of being HIV positive as demanding as the medical or physical problems that HIV presented. For many young people in this study it is their personal resources rather than external support that enable them to make sense of HIV.

Theoretical Contributions

This thesis contributes to debates about 'biographical disruption' (Bury 1982), 'critical moments' (Thomson et al. 2002), stigma, identity and young people. It extends the concept of biographical disruption and applies it, as suggested by Williams (2000), to young people born with a long-term life limiting condition. Biographical disruption is a dynamic process for these young people and is interspersed by 'critical moments' (Thomson et al. 2002) that serve to remind them of their difference. Young people with HIV make sense of disruption in order to construct and maintain a new identity as they become adults; this process is mediated via the stigma attached to HIV as well as the disease process. In the transition to adulthood young people encounter 'critical moments', such as leaving school, starting college or work and the forming of relationships and young people have to deal with the fear of stigma and discrimination should their HIV status be discovered. This study found that the experience of 'biographical disruption' and 'critical moments' may have different consequences for young people than for adults. Some young people identified positive effects of biographical disruption and cited HIV as a positive influence on their lives. Being born with a highly stigmatised condition disrupts a

young person's biography in a distinct way. Thus the biographical disruption caused by HIV is particularly complex because the attached stigma creates an additional dimension of disruption not associated with other conditions. The disruption is therefore more complex in that HIV introduces secrecy and concealment into the management of their condition and highlights the impact of previous secrecy people engaged in to hide their status from them.

Although previous studies suggested that those with already disrupted lives may not experience the same degree of disruption (Caricaburu and Pierret 1995; Ciambrone 2001), the findings of this study suggest otherwise. A diagnosis of HIV represents a major 'critical moment' (Thomson et al. 2002) for young people and they engage in a continual process of reassessing and adapting to changes that HIV brings. The stigmatising nature of the social discourse of HIV affects young peoples' view of self. This discourse is internalised by young people and affects how they fear 'others' may view them.

Practical Implications

Many of the findings presented in this thesis contribute to debates by academics on the experiences of young people born with HIV. The central debates highlighted in the literature focus on disclosure, sexual relationships and vulnerability to mental health problems (Fielden et al. 2006.) Most debates on this topic are conducted within a medical framework of enquiry with a focus on quantitative studies and reference to medical notes, rather than being explored from a young person's perspective. Until now the perceived needs or difficulties of young people have been focused on the medical management of HIV as currently in the UK most care for young people with HIV is found within a medical context. As the findings from this study reveal, not all the difficulties young people identify are medical; many are concerned with the management of social interaction and relationships. The young people in the main appear to deal well with the medical challenges whereas the social ramifications of being HIV positive may raise more difficulties. The rights of the child within the disclosure process and implications of an HIV

diagnosis for young people require more attention (Alderson 1995). Likewise, understanding the family dynamic and relationships between young people and parents may help young people cope better with a diagnosis of HIV. The concept of 'critical moments' used in this study may be helpful in enabling practitioners and service providers to look at the trajectory of HIV and anticipate likely key 'critical moments' for young people and develop appropriate and improved support for these young people. The way forward may be to explore joint working between medical and social researchers in order to better understand the wider implications of living with HIV for young people and their families and develop services that offer ongoing support for young people.

9.3. Areas for Future Research

This thesis demonstrates the value of studying the complex experiences of young people born with HIV. Although this group is not increasing at a fast rate in the UK, the population of perinatally infected young people is increasing in high prevalence countries (NAM, 2009). In the UK the largest cohort of young people perinatally infected are currently between the ages of 10 and 12 (CHIPS Data 2009), therefore findings from this study could directly benefit this group. There is little previous research on the social or emotional impact of HIV on young people who have grown up with the condition thus there is a need to explore this topic with the same rigour as medical research. This thesis has revealed a number of potential areas for future research.

- As in previous studies (Brown et al. Fielden et al. 2006) young people in this study identify the isolation that HIV can bring as they remove themselves or feel excluded from friendship networks, other existing social networks and at times, family. Further research into the current support provision and support needs of young people and parents is required.
- 'Critical moments' in a young person's HIV trajectory could be anticipated. Certain transitions points or moments in their life course may result in increased vulnerability and additional support may be beneficial at these times.

- Existing studies highlight the potential vulnerability of HIV - positive young people to mental health problems (NAM 2009). Further research will increase understanding of the impact of HIV on the mental well-being of young people. Identifying specific interventions or times of particular stress and vulnerability in order to provide appropriate and timely support should be explored.
- This thesis demonstrates the difficulties young people experience with the disclosure process; a greater understanding of young peoples' views in relation to the disclosure of HIV status and follow up care could be of benefit. How information and communication is managed and controlled within families, with parents and siblings is central to disclosure.
- Findings from this study identify the challenges for families affected by HIV. Relationships and communication within the family are of particular concern to young people and further research into the impact on HIV upon families and uninfected siblings may be of benefit.
- Findings from this thesis confirm the important role peers play in a young person's life. However, the stigma and fear of stigma appears to isolate young people from their friends and social networks because they fear the consequences of telling others. This study indicates that it can be helpful and supportive to tell a friend. These findings should be considered in relation to practice where young people are not generally encouraged to consider revealing their status to their peers. For older young people there may be benefits in telling a good friend.
- This study indicates the importance of constructive sexual health education and support in helping young people to manage disclosure in sexual relationships. Further research is needed to establish strategies to enable young people manage sexual relationships in light of HIV infection.

- Young people in this thesis highlight the difficulties they experience in school, particularly the perceived negative and stigmatising attitudes and knowledge of teachers and pupils. Research is needed to further explore a) how the issue of HIV is discussed in schools and b) how HIV positive children and young people experience this.
- These young people are unique in that they have lived all their lives with HIV infection. Although there are longitudinal medical studies in places across Europe (PENTA. 2008), there is currently no longitudinal study on the social and emotional impact on young people born with HIV and in particular the influence on identity. As the first generation of young people to survive and live with HIV into young adulthood, the opportunity for a longitudinal study should be explored.

9.4. Concluding remarks

This thesis has presented an in-depth exploration of the experiences of young people born with HIV and contributes to the understanding of this small but unique population. Through detailed descriptions and analysis of young people's; lives, beliefs and values many themes emerged. The study highlights the interplay between HIV, biographical disruption, critical moments, stigma and identity. The thesis has argued that HIV disrupts a young person's biography, and uniquely impacts on their past as well as future biography. Young people experience disruption as a process that is interspersed with critical moments that serve to remind them of difference. They experience biographical disruption differently than adults and in most cases HIV further disrupts already disrupted lives. They are continually making sense of the disruption arising from being HIV positive and the 'critical moments' the condition brings, in order to construct and maintain a new identity as they move into adulthood. Biographical disruption and critical moments are mediated through the stigma of HIV and changes fundamentally a young person's view of self. Young people engage in a continual process of re-assessing and adapting to changes that HIV brings and they have to respond in an appropriate way. They have to re-

consider their identity in light of this stigmatising and progressive condition and adapt to the possibility of a premature death.

REFERENCES

Abadia-Barrero, C. E. and Castro, A. (2006). Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil, *Social Science and Medicine*, 62:1219-1228.

Abadia-Barreo, C. E. and La Russo, M. D. (2006). The Disclosure Model versus a Developmental Illness Experience Model for Children and Adolescents Living with HIV in Sao Paulo, Brazil, *AIDS Patient Care and STD's*, 20(1):36-43.

Alderson, P. (1995). *Listening to Children: Children, Ethics and Social Research*, Barnardos, Barking, London.

Alderson, P. (2004). Ethics. In Fraser, S., Lewis, V., Ding, S., Kellett, M., and Robinson, C. (Eds.), *Doing Research with Children and Young People*, London, Sage Publication and The Open University.

Aldrovandi, G. M. (2005). The natural history of pediatric disease. In *Textbook of Pediatric HIV Care*. Eds: Zeichner, S. and Read, J. Cambridge: Cambridge University Press: 111-133.

Alonzo, A. A. and Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory, *Social Science and Medicine*, 41(3), 303-315.

Anderson, J. and Doyal, L. (2004). Women from Africa living with HIV in London: a descriptive study, *AIDS Care*, Vol. 16, No. 1, 95-105.

- Armistead, L., Tannenbaum, L., Forehand, R., Morse, E., and Morse, P. (2001). Disclosing HIV status: Are mothers telling their children? *Journal of Pediatric Psychology*, 26 (1), 11-20.
- Aronson, J. (1994), A Pragmatic View of Thematic Analysis, *The Qualitative Report*, Vol 2, No 1, Spring.
- Arpadi, S. M., Horlick, M., Thornton, J., Wang, J., Kotler, D. P. (2002). Bone mineral content is lower in prepubertal HIV infected children, *Journal of Acquired Immune Deficiency Syndrome*, 29(5) 450-458.
- Asbring, P. (2001). Chronic illness – a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia, *Journal of Advanced Nursing*, 34(3):312-319.
- Atkin, K. and Ahmad, W. I. U. (2001). Living a 'normal' life: Young people coping with Thalassaemia major or Sickle Cell Disorder, *Social Science and Medicine*, Vol. 53, Issue 5:615-626.
- Bachanas, P. J., Kullgren, K. A., Suzman Schwartz, K. (2001). Predictors of psychological adjustment in school-age children infected with HIV, *Journal of Pediatric Psychology*, 26:343-352.
- Barroso, J. and Powell-Cope, G. M. (2000). Metasynthesis of Qualitative Research on Living With HIV Infection, *Qualitative Health Research*, Vol.10, No.3:340-353.
- Batterman, P., Rice, E., Rotherham-Borus, M. J. (2005). Predictors of Serostatus Disclosure to Partners Among young People Living with HIV in the Pre- and Post – HAART Eras, *AIDS and Behavior*, Vol. 9, No. 3:281-287.

Battles, H. B. and Wiener, L. S. (2002). From adolescence through young adulthood: psychosocial adjustment associated with long term survival of HIV, *Journal of Adolescent Health*, 30(3):161-181.

Bauman, Z. (1999), *Globalization, The Human Consequences*, Cambridge, Polity Press.

Baumeister, R. F. (1991). *Meanings of Life*, New York: The Guildford Press.

Baumgartner, L. M. (2002). Living and learning with HIV/AIDS: Transformational Tales Continued, *Adult Education Quarterly*, 53:44.

Beale, E. A., Baile, W. F., Aaron, J. (2005). Silence is Not Golden: Communicating with Children Dying from Cancer, *Journal of Clinical Oncology*, Vol.23, No. 15, 3629-3631.

Beck, U. (1992), *Risk Society: Towards a New Modernity*, London, Sage.

Beck, U. and Beck-Gernsheim, E. (1995). *The Normal Chaos of Love*, Cambridge: Polity Press.

Becker, E. (1997). *The Denial of Death*, New York Free Press.

Becker, F. and Wenzel, G. P. (2007). Searching for Pathways in a Landscape of Death: Religion and AIDS in East Africa, *Journal of Religion in Africa*, Vol. 37, No. 1:1-15.

Becker, G. (1981). Coping with Stigma: Lifelong adaptation of deaf people, *Social Science, Medicine and Medical Anthropology*, 15B(1):21-24.

Bell, N. B., Martinez, J., Botwinick, G., Shaw, K., Walker, L. E., Dodds, S., Sell, R. L., Johnson, R. L., Friedman, L. B., Sotheran, J. L., Siciliano, C. (2003). Case Finding for HIV –Positive Youth: A Special Type of Hidden Population, *Journal of Adolescent Health*, 33S: 10-22.

Berger, B. E., Ferrans, C. E., Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale, *Research in Nursing and Health*, 24(6):501-529.

Bertaux, D. and Thompson, P. (1997), *Pathways to Social Class: A Qualitative Approach to Social Mobility*, Oxford: Clarendon.

Blasini, I., Chantry, C., Cruz, C., Ortiz, L., Salabarría, I., Scalley, N., Matos, B., Febo, I., Diaz, C. (2004). Disclosure model for pediatric patients living with HIV in Puerto Rico: design, implementation and evaluation, *Journal of Development Behaviour Pediatrics*, 25(3):181-189.

Bluebond-Langner, M. (1978) *The private worlds of dying children*, Princeton: New Jersey, Princeton University Press.

Bluebond-Langner, M., Perkel, D., Goetz, I. (1990). Children's knowledge of cancer and its treatment: the impact of an oncology experience, *Journal of Pediatrics* 116(2), 207-214.

Bluebond- Langner, M. (1996). *In the Shadow of Illness Parental and Siblings of the Chronically Ill Child*, Princeton, New Jersey, Princeton University Press.

Bond, K., Dorrell, J., Honigsbaum, N. (2000). *What Do The Children Tell Us?* Project Report, European Forum on HIV/AIDS Children and Families, London.

Bor, R. and Elford, J. (1998). *The Family and HIV Today*, Cassell.

Brashers, D. E., Neidig, J. L., Reynolds, N. R., Haas, S. M. (1998). Uncertainty in illness across the HIV/AIDS trajectory, *Journal of Association of Nurses and AIDS Care*, 9(1):66-77. British Medical Association (2001). *Guidelines for Talking to Children*, London.

Britto, M. T., Garrett, J. M., Dugliss, M. A. J., Daeschner, C. W., Johnson, C. A., Leigh, M. W., Majure, J. M., Schultz, W. H., Konrad, T. T. (1998). Risky Behavior in Teens with Cystic Fibrosis or Sickle Cell Disease: A Multicenter Study, *Pediatrics*, Vol. 101, No. 2: 250-256.

Brown, L. K., Lourie, K. J., Pao, M. (2000). Children and Adolescents Living with HIV and AIDS: A Review, *Journal of Child Psychology and Psychiatry*, Vol. 41, No.1:81-96, Cambridge University Press.

Bryman, A. (2004). *Social Research Methods*, Oxford, Oxford University Press.

Buchacz, K., Rogol, A. D., Lindsaey, J. C., Wilson, C. M., Hughes, M. D., Seage, G. R., Oleske, J. M., Rogers, A. S., Rogers, A. S. (2003). Delayed onset of pubertal development in children and adolescents with perinatally acquired HIV infection, *Journal of Acquired Immune Deficiency Syndromes*, 2003, 1;33(1):56-65.

Bunting, S. M. (1996). Sources of stigma associated with women with HIV, *Advances in Nursing Sciences*, Vol. 19, Issue 2:64-73.

Bury, M. (1982). Chronic Illness as a Biographical Disruption, *Sociology of Health & Illness*, 4:162-182.

Bury, M. (1988). Meanings at risk: the experience of arthritis. In Anderson, R. and Bury, M. (1988). *Living with Chronic Illness: The Experiences of Patients and Their Families*, London, Unwin Hymen.

Bury, M., (1991). The sociology of chronic illness: a review of research and prospects, *Sociology of Health & Illness*, Vol.13, No. 4: 451-468.

Brannen, J. and Nilsen, A., (2002), Young People's Time Perspectives: from Youth to Adulthood, *Sociology*, 36:513-537.

Caldwell, J. C., Caldwell, P., Caldwell, B. K., Pieris, I. (1998). The Construction of Adolescence in a Changing World: Implications for Sexuality, Reproduction, and Marriage, *Studies in Family Planning*, Vol.29, No. 2:137-143.

Carragher, D. J. (2002). Trying to Hide: A Cross-National Study of Growing Up for Non-Identified Gay and Bisexual Male Youth, *Clinical Child Psychology and Psychiatry*, Vol.7, No. 3: 457-474.

Carricaburu, D. and Pierret, J. (1995). From biographical disruption to biographical reinforcement: the case of HIV positive men, *Sociology of Health & Illness*, Vol. 17, Issue 1: 65-88.

Chapman, E. (2002). Impact of negative media representation, *AIDS Patient Care and STDs*, 16(4):173-177.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill, *Sociology of Health & Illness*, Vol. 5, No. 2: 168-195.

- Charmaz, K. (1987). Struggling For A Self: Identity Levels Of the Chronically Ill, *Research in the Sociology of Health Care*, Vol. 6, 283-321.
- Charmaz, K. (1995). The Body, Identity, and Self: Adapting to Impairment, *Sociological Quarterly*, 36 (4) Fall 657-680.
- Charmaz, K. (1997). *Good Days, Bad Days: The Self in Chronic Illness and Time*, Rutgers University Press, New Brunswick, New Jersey.
- Charmaz, K. (1999). Stories of suffering: subjective tales and research narratives, *Qualitative Health Research*, Vol.9, No. 3, 362-382.
- Charmaz, K. (2002). Stories and Silences: Disclosure and self in chronic illness, *Qualitative Inquiry*, Vol. 8, No. 3, 302-328.
- Charmaz, K. (2003). Qualitative Interviewing and Grounded Theory Analysis. In Holstein, J. A. and Gubrium, J. F. (Eds.) *Inside interviewing: New lenses, new concerns*, Sage.
- Chesler, M. A. and Barbarin, O. A. (1987). *Childhood Cancer and the Family: Meeting the challenge of stress and support*, Routledge
- Chesney, M. (2003). Adherence to HAART Regimens, *AIDS Patient Care and STDs*, Vol17, No. 4:169-177.
- CHIPS Data (2009) Collaborative HIV Paediatric Study, Annual Report, London.
- CHIVA - Children HIV and AIDS Association (2009). Guidelines on Disclosure of HIV status to Children, London.

Ciambrone, D. (2001). Illness and other assaults on the self: the relative impact of HIV/AIDS on women's lives, *Sociology of Health & Illness*, Vol. 23, Issue 4, 517-540.

Claflin, C. J. and Barbarin, O. A. (1991). Does 'telling' less protect more? Relationships among age, information, disclosure and what children with cancer see and feel, *Journal of Pediatric Psychology*, 16(2): 169-191.

Clarke, S. A., Davies, H., Jenney, M., Glaser, A., Eiser, C. (2005). Parental communication and children's behaviour following diagnosis of childhood leukaemia, *Psycho-oncology*, Vol. 14, Issue 4, 274-281.

Coffey, A.(1999). *The Ethnographic Self: Fieldwork and the Representation of Identity*, London, Sage Publication.

Cogan, J. and Herek, G. (1998). In Smith, R. A. (Eds). *Stigma: The Encyclopaedia of AIDS: A Social and Political, Cultural and Scientific Record of the HIV Epidemic*. Chicago: Fitzroy Dearborn.

Conway, M. (2006). *Developing support services for children, young people and families living with HIV*, National Children's Bureau, London.

Cooper, E. S., Risley, C. L., Drake, L. J., Bundy, D. A. P. (2007). HIV as part of the life of children and youth, as life expectancy increases: Implications for Education, *Journal of International Cooperation in Education*.

Copp, G. and Field, D. (2002). Open awareness and dying: the use of denial and acceptance as coping strategies by hospice patients, *Nursing Times Research*, 7:118-127.

Corbin, J. and Strauss, A. (1987). Accompaniments of chronic illness: changes in body, self, biography and biographical time, *Research in the Sociology of Health Care*, 6:249-281.

Corrigan, P.W., Penn, D. I. (1999). Lessons from social psychology on discrediting psychiatric stigma, *American Psychology*. 54:765-76.

Courtenay, B. C., Merriam, S. B., Reeves, P. M. (1998). The Centrality of Meaning-Making in Transformational Learning: How HIV Positive Adults Make Sense of Their Lives, *Adult Education Quarterly*, Vo. 48, Issue 2:65-85.

Courtenay, B. C., Merriam, S. B., Reeves, P. M., Baumgartner, L. M. (2000). Perspective transformation over time: A two-year follow up study of HIV positive adults, *Adult Education Quarterly*, 50:102-119.

Crandall, C. S. and Coleman, R. (2002). AIDS related stigmatization and the disruption of social relationships, *Journal of Social and Personal Relationships*, 9(2):163-177.

Crawford, R. (1994). The boundaries of the self and the unhealthy other: reflections on health, culture and AIDS, *Social Science and Medicine*, 38(10):1347-1365.

Cree, V. E., Kay, H., Tisdall, K. (2002). Research with children: sharing the dilemmas, *Children and Family Social Work*, Vol.7, No.1: 47-56(10).

Cree, V. E., Kay, H., Tisdall, K., Wallace, J. (2004). Stigma and Parental HIV, *Qualitative Social Work*, Vol. 3(1):7-25.

Creed, W. E. D. (2003). Voice lessons: tempered radicalism and the use of voice and silence, *Journal of Management Studies*, 40:1503-1536.

Crew Nelms, B. (1989). Emotional behaviours in chronically ill children, *Journal of Abnormal Child Psychology*, Vol. 17, No. 6, 657-668.

Crimp, D. (2004). *Melancholia and Moralism: Essays on AIDS and Queer Politics*, MIT Press.

Crocker, J., Major, B., Steele, C. (1998). Social stigma. In D. T. Gilberts, S. T. Fiske, and G. Lindzey (Eds.), *Handbook of Social Psychology* 4th Edition, Vol. 2: 504-553, Boston: McGraw-Hill.

Crocker, J. and Quinn, D. M. (2000). Social Stigma and the Self: Meanings, Situations and Self-esteem. In Heatherton, T. F., Kleck, R. E., Hebl, M. R., Hull, J. G. (Eds.) *The Social Psychology of Stigma*, The Guildford Press. London.

Cromer, B., Enrile, B., McCoy, K., Gerhardstein, M. J., Fitzpatrick, M., Judis, J. (1990). Knowledge, Attitudes and Behaviour Related to Sexuality in Adolescents with Chronic Disability, *Developmental Medicine & Child Neurology*, Vol. 32, Issue 7: 602-610.

Crossley, M. L. (1999). Making Sense of HIV Infection: Discourse and Adaptation to Life with a Long-term HIV Positive Diagnosis, *Health*, Vol. 3, No.1, 95-120.

Dahlquist, L. M. and Taub, E. A. (1991). Family Adaptation to Family Cancer, in J. Vincent (Eds.), *Advances in Family Interventions, Assessment and Theory* Vol. 5, 123-150, London, Kingsley.

Davies, M. L. (1997). Shattered assumptions: time and the experience of long term HIV positivity, *Social Science and Medicine* 44(5):56-71.

De Bruyn, T. (1998). *HIV/AIDS and Discrimination: A Discussion Paper*. Montreal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society.

de Martino, M., Toro, P.A., Balducci, M., Galli, L., Gabiano, C., Rezza, G., Pezzotti, P. (2000), Reduction in mortality with availability of antiretroviral therapy for children with perinatal HIV-1 Infection, *JAMA*, 284(2):190-7.

de Martino, M., Tovo, P-A., Galli, L., Gabiano, C., Chiarelli, F., Zappa, M., Gattinara, G. C., Bassetti, D., Giacomet, V., Chiappini, E., Duse, M., Garetto, S., Caselli, D. (2001). Puberty in perinatal HIV-1 infection: a multicentre longitudinal study of 212 children, *AIDS*, Vol. 15, Issue 12:1527-1534.

Deacon, H., Stephney, I., Prosalendis, S. (2005). Understanding HIV/AIDS Stigma: A theoretical and methodological analysis, *HSRC Research*, London.

Deatrick, J. A. and Faux, S.A. (1991). Conducting Qualitative Studies with Children and Adolescents: A contemporary dialogue, In Morse, J.M. *Qualitative Nursing Research* (2nd edition) Newbury Park: Sage.

DeMatteo, D., Harrison, C., Arneson, C., Salter Goldie, R., Lefebvre, A., Read, S. E., King, S. M. (2002). Disclosing HIV/AIDS to children: the paths to truth-telling, *Psychology, Health and Medicine*, Vol 7, No.3:339-356.

Dixon-Woods, M., Young, B., Heney, D, (2002). Childhood cancer and user's views: a critical perspective, *European Journal of Cancer Care*, 11(3):173-177.

Dray-Spira, R. (2003). Social health inequalities during the course of chronic HIV disease in the era of highly active antiretroviral therapy, *AIDS*, Vol. 17(3)14:283-290.

Drew, S. (2003). Self-Reconstruction and Biographical Revisioning: Survival Following Cancer in Childhood or Adolescence, *Health* (London), 7:181-199.

Du Bois-Reymond, M. (1998), 'I Don't Want to Commit Myself Yet': Young People's Life Concepts, *Journal of Youth Studies*, Vol 1, No 1: 52-79.

Eder, D. and Fingerson, L. (2003). Interviewing Children and Adolescents. In Holstein, J. A. and Gubrium, J. F. *Inside Interviewing: New Lenses, New Concerns*, Sage.

Elford, J., Ibrahim, I., Bukutu, C. Anderson, J. (2007). Sexual behaviour of living with HIV in London: implications for HIV transmission, *AIDS*, Vol.21, Supplement 1:63-70.

Emlet, C. A. (2006). A Comparison of HIV stigma and disclosure patterns between older and younger adults living with HIV/AIDS, *AIDS Patient Care and STDs*, 20, 350-358.

Erikson, E. H. (1956). *The Problem of Ego Identity*, Journal of American Psychoanalytic Association, Vol. 4, No. 1: 56-121.

Exley, C. and Letherby, G. (2001). Managing a Disrupted Lifecourse: Issues of Identity and Emotion Work, *Health*, Vol.5, No.1: 112-132.

Ezzy, D. (2000). Illness narratives: time, hope and HIV, *Social Science and Medicine* 50:605-617.

Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery, *Sociology of Health & Illness*, Vol. 26, Issue 2: 242-261.

Fee, E. and Fox, D. M. (1992). *The Making of a Chronic Disease*, University of California.

Feiring, C., Taska, L. and Lewis, M. (1999). Age and gender differences in children's and adolescents' adaptation to sexual abuse, *Child Abuse & Neglect*, Vol.23, Issue 2:115-128.

Feldman, M. (2003) The challenges of working with perinatally infected adolescents: Clinical and concrete possibilities. In Willinger, B. I., Rice, A. (Eds) *A History of AIDS Social Work in Hospitals: A daring response to an epidemic*, 277-286, Haworth Press, New York.

Fereday, J. and Muir-Cochrane, E. (2006), Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development, *International Journal of Qualitative Methods*, 5(1):80-92.

Fernet, M., Proulx-Boucher, K., Richard, M. E., Levy, J. J., Otis, J., Samson, J., Massie, L., Lapointe, N., Theriault, J., Trottier, G. (2007). Issues of sexuality and prevention among adolescents living with HIV/AIDS since birth, *The Canadian Journal of Human Sexuality*, Vol. 16 (3-4):101-111.

Ferris, M., Burau, K., Schweitzer, S., Mihale, N., Preda, A., Ross, M., Kline, M. (2007). The influence of disclosure of HIV diagnosis in a cohort of Romanian children and teens, *AIDS Care*, 19(9):1088-1094.

Field, D. and Copp, G. (1999). Communication and awareness about dying in the 1990's, *Palliative Medicine*, 13;459-468.

Field, D. and Copp, G. (2002). Open Awareness and Dying: the use of denial and acceptance as coping strategies by hospice patients, *Nursing Times Research*, Vol.7, No. 2: 118-127.

Fielden, S. J., Scheckter, L., Chapman, G.E., Aliment, A., Forbes, J. C., Shelp, S., Cadell, S., Frankish, J.C. (2006). Growing up: Perspectives of children, families and service providers regarding the needs of older children with perinatally - acquired HIV, *AIDS Care*, 18(8):1050-1053.

Fife, B. L. and Wright, E. R. (2000). The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer, *Journal of Health and Social Behaviour*, 41:50-67.

Flanagan-Klygis, E., Ross, L .F., Lantos J., Frader, J., Yogev, R. (2001). Disclosing the diagnosis of HIV in pediatrics, *Journal of Clinical Ethics*, 12(2):150–157.

Flowers, P., Davis, M., Hart, G., Rosengarten, M., Frankis, J., Imrie, J. (2006). Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK, *Psychology and Health*, 21(1):109-122.

Foster, C. and Lyall, E. G. H. (2005). Children with HIV: improved mortality and morbidity with combined antiretroviral therapy, *Current Opinion in Infectious Diseases*, 18.

Foster, C., Waelbrouck, A., Peltier, A. (2007). Adolescent and HIV Infection, *Current Opinion in HIV and AIDS*, Vol.2, Issue 5:431-436.

Frable, D. E. S., Blackstone, T., Scherbaum, C. (1990). Marginal and mindful: Deviants in social interactions, *Journal of Personality and Social Psychology*, 59: 140-149.

Frankenberg, R. (1986). Sickness as cultural performance: drama, trajectory, and pilgrimage root metaphors and the making of social of disease, *International Journal of Health Service*, 16(4):603-626.

Franklin, S., Lim, H. J., Rennie, K M., Eastwood, D., Cuene, B., Havens, P. (2005).

Longitudinal Intellectual Assessment of Children with HIV infection, *Journal of Clinical Psychology in Medical Settings*, Vol. 12, No. 4:367-376.

Fraser, S., Lewis, V., Ding, S., Kellet, M., Robinson, C. (Eds.), (2004). *Doing Research with Children and Young People*, Sage Publication, London and The Open University.

Frederick, T., Thomas, P., Mascola, L., Hsu, H. W., Rakusan, T., Weedon, J., Bertolli, J. (2000). Human immunodeficiency virus infected adolescents: a descriptive study of older children in New York City, Los Angeles County, Massachusetts and Washington, D.C., *Pediatric Infectious Disease Journal* ,19(6):551-555.

Frink Sherman, B., Bonanno, G.A., Weiner, L. S., Battles, H. B. (2000). When Children Tell Their Friends They Have AIDS: Possible Consequences for Psychological Well-Being and Disease Progression, *Psychosomatic Medicine*, 62:238-247.

Frydenberg, E., (1997). *Adolescent coping: Theoretical and research perspectives*. Routledge, London.

Funck-Brentano, I. (1995). Informing a child about his illness in HIV infection: words and meaning, *Psychiatric Infant*, 38(1):109–139.

Funck-Brentano, I., Costagiola, D., Seibel, N., Straub, E., Tardieu, M., and Blanche, S. (1997). Patterns of disclosure and perceptions of the human immunodeficiency virus in infected elementary school-age children, *Archives of Pediatric Adolescent Medicine*, 151: 978-985.

Gaughan, D. M. Hughes, M.D. Seage, G. R. Selwyn, P. A. Carey, V. J. Gortmaker, S. L. Oleske, J. M. (2002). The Prevalence of Pain in Pediatric Human Immunodeficiency

Virus/Acquired Immunodeficiency Syndrome as Reported by Participants in the Pediatric Late Outcomes Study, *Pediatrics* Vol. 109 No.6:1144 -1152.

Gaughan, D. M., Hughes, M. D., Oleske, J. M., Malee, K., Gore, C., Nachman, S. (2004). Psychiatric Hospitalizations among Children and Youths with Human Immunodeficiency Virus Infection, *Pediatrics*, Vol. 113, No. 6:544-551.

Giacomet, V., Albano, F., Starace, F., de Franciscis, A., Giaquinto, C., Castelli Gattinara, G., Bruzzese, E., Gabiano, C., Galli, L., Vigano, A., Caselli, D., Guarino, A. (2003). Adherence to antiretroviral therapy and its determinants in children with human immunodeficiency virus infection: a multicentre, national study, *Acta Paediatrica* Vol. 92, No.12:1398-1402, Taylor and Francis.

Gibb, D. M., Duong, T., Tookey, P. A., Sharland, M., Tudor-Williams, G., Novelli, K., Butler, K., Riordan, A., Farrelly, L., Masters, J., Peckham, C. S., Dunn, D.T. (2003). Decline in mortality, AIDS, and hospital admissions in perinatally infected HIV-1 infected children in the United Kingdom and Ireland, *British Medical Journal*, 327:1019.

Gielen, A. C., O'Campo, P. Faden, R. R., Eke, A. (1997). Women's Disclosure of HIV Status: Experiences of Mistreatment and Violence in an Urban Setting, *Women and Health*, Vol. 25, Issue 3:19-31.

Giddens, A. (1991), *Modernity and Self Identity: Self and Society in the Late Modern Age*, Cambridge: Polity.

Giles, D. C. and Maltby, J. (2004). The role of media figures in adolescent development: relations between autonomy, attachment, and interest in celebrities, *Personality and Individual Differences*, 36:813-822.

Gilman, S. L. (1988). *Disease and representation: Images of illness from madness to AIDS*, Cornell University Press, Ithaca New York.

Gilmore, N and Somerville, M.A. (1994). Stigmatization, Scapegoating and Discrimination in Sexually Transmitted Diseases: Overcoming 'Them' and 'Us', *Social Science and Medicine*, 39(9):1339-1358.

Glaser, B. G. and Strauss, A. L. (1964). Awareness Context and Social Interaction, *American Sociological Review*, Vol.29, No.5, 669-679.

Glaser, B. G. and Strauss, A. L. (1965). *Awareness of Dying*, Chicago, Aldine Transaction.

Glaser, B. G. and Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Aldine Transaction.

Glaser, B. (1992). *Basics of grounded theory analysis: emergence V forcing*, Sociology Press Mill, CA.

Goffman, E, (1963). *Stigma: Notes on the Management of Spoiled Identity*, Englewood Cliffs, New Jersey: Prentice Hall.

Good, B. J. and Del Vecchio Good, M. J. (1994). In the subjunctive mode: epilepsy narratives in Turkey, *Social Science and Medicine*, 38(6):835-842.

Gosling, S. A., Burns, J., Hirst, F. (2004). Children with HIV in the UK: A Longitudinal Study of Adaptive and Cognitive Functioning, *Clinical Child Psychology and Psychiatry* 1359- 1045, Vol. 9 (1):25-37.

Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed:' felt and enacted stigma amongst parents of high functioning autism, *Sociology of Health & Illness*. Vol. 24. No.6:734-749.

Green, G. and Smith, R.(2004) The psychosocial and health needs of HIV- positive people in the United Kingdom: a review, *HIV Medicine*, 5, (Suppl.1):5-46.

Greenberg, M. A. and Stone, A. A. (1992). Emotional disclosure about traumas and it's relation to health: effects of previous disclosure and trauma severity, *Journal Personal Social Psychology*, 1992; 63:75-84.

Gringer, C. and Thomas, C. (2001). Young Adults with Cancer: The effects of illness on parents and families, *International Journal of Palliative Nursing*, Vol.7, No.4:162-170.

Grinyer, A. (2007). The biographical impact of teenage and adolescent cancer, *Chronic Illness*, 3:265-277.

Grove, K. A., Kelly, D. P., Liu, J. (1997). 'But nice girls don't get it'. Women, symbolic capital and the social construction of AIDS, *Journal of Contemporary Ethnography*, 26: 317-377.

Grubman, S., Gross, E., Lerner-Weiss, N., Hernandez, M., Mcsherry, G. D., Hoyt, L. G., Boland, M., Oleske, J. M. (1995). Older children and adolescents living with perinatally acquired human immunodeficiency virus infection, *Pediatrics* Vol.95, Issue 5:657-663.

Gubrium, J. F. and Holstein, J. A. (Eds.) (2002). *Handbook of Interview Research*, Sage., London.

Hardy, M. S., Routh, D. K., Armstrong, F. D. (1995). Interpersonal distance and coping in children with HIV and cancer, *Child Health Care*, 24(2):119–131.

Harris, M. (2009). Troubling biographical disruption: narratives of unconcern about hepatitis C diagnosis, *Sociology of Health & Illness*, Vol. 31, No. 7, 1-15.

Havens, J.F., Mellins, C. A., Hunter, J. (2002). Psychiatric Aspects of HIV/AIDS in childhood and adolescence. In Rutter M, Taylor E, (Eds.), *Child and Adolescent Psychiatry: Modern Approaches*, 4:828-841, Oxford, UK: Blackwell.

Health Protection Agency (HPA), (2009). HIV and AIDS in the United Kingdom quarterly update: to the end of March 2009, <http://www.hpa.org.uk/cdr/pages/hiv> , Accessed 26/09/09.

Heaphy, B. (1996). Medicalisation and identity formation: identity and strategy in the context of AIDS and HIV, *Explorations in Sociology*, Macmillan.

Heath, S., Charles, V., Crow, G., Wiles, R. (2006). Informed consent, gatekeepers and go-betweens: negotiating consent in child and youth centres institutions, *British Educational Research Journal*, 33(3) 403–417. <http://eprints.soton.ac.uk/51929>. Accessed on 10.07.09.

Hebl, M. R., Tickle, J., Heatherton, T. F. (2000). Awkward Moments in Interactions between Non-stigmatised and Stigmatised Individuals. In Heatherton, T. F., Kleck, R. E., Hebl, M.R., Hull, J, G. (Eds.), *The Social Psychology of Stigma*, p 275-306, The Guildford Press, London.

Herek, G. M. and Glunt, E. K. (1988). An epidemic of stigma: Public reactions to AIDS. *American Psychologists*, 43 (11), 886-891.

Herek, G. M. and Capitanio, J. P. (1998). Symbolic Prejudice or fear of Infection? A Functional Analysis of AIDS Related Stigma Among heterosexual Adults, *Basic and Applied Social Psychology*, 1532-4834, Vol. 20, Issue 3: 230-241.

Herek, G. M. (2002). Thinking about AIDS and Stigma: A Psychologist's Perspective, *Journal of Law, Medicine & Ethics*, 30:594-607.

Herek, G. M., Capitanio, J. P., Widaman, K. F. (2002). HIV Related Stigma and Knowledge in the United States: Prevalence and Trends, 1991-1999, *American Journal of Public Health*, Vol. 92, No. 3:371-377.

Herek, G. M., Widaman, K. F., Capitanio, J. P. (2005). When sex equals AIDS: Symbolic stigma and heterosexual adults' inaccurate beliefs about sexual transmission of AIDS, *Social Problems*, 52(1):15-37.

Holland, J. and Thomson, R. (2009), Gaining Perspective on Choice and Fate: Revisiting critical moments, *European Societies*, 11(3) 451-469.

Hosek, S. G., Harper, G. W., and Robinson, W. L. (2002). Identity development in adolescents living with HIV, *Journal of Adolescence*, 25:355-364.

Hughes, E. C. (1945). Dilemmas and Contradictions of Status, *American Journal of Sociology*, 50:353-359.

Hyden, L. C. (1997). Illness and narrative, *Sociology of Health & Illness*, Vol. 19, Issue 1:48-69.

Instone, S. L. (2000). Perceptions of children with HIV infection when not told for so long: Implications for diagnosis disclosure, *Journal of Pediatric Health Care*, 14:235-243.

Jacobson Jr., C. J., Luckhaupt, S. E., Delaney, S., Tsevat, J. (2006). Religio-Biography, Coping and Meaning-Making among Persons with HIV/AIDS, *Journal for the Scientific Study of Religion*, 45(1):39- 56.

Janoff-Bulman, R. (1992). *Shattered assumptions: towards a new psychology of trauma*. New York: The Free Press.

Jessop, D. J. and Stein, R. E. K. (1985). Uncertainty and its relation to the psychological and social correlates of chronic illness in children, *Social Science and Medicine*, 20:215-222.

Joffe, H. (1999) *Risk and 'the other'*. Cambridge: Cambridge University Press.

Jones, E. E., Farina, A., Hastorf, A. H., Markus, H., Miller, D. T., Scott, R. A. (1984). *Social stigma: The psychology of marked relationships*, New York: Freeman.

Judd, A., Doerholt, K., Tookey, P. A., Sharland, M., Riordan, A., Menson, E., Novelli, V., Lyall, E. G. H., Masters, J., Tudor-Williams, G., Duong, T., Gibb, D. M. (2007). Morbidity, Mortality, and response to treatment by Children in the United Kingdom and Ireland with Perinatally Acquired HIV Infection during 1996-2006: Planning for Teenage and Adult Care, *Clinical Infectious Diseases*, 45:918-924.

Juhasz, J. (1993). *Women and AIDS*, Sage.

Karon, M. and Vernick, J. (1968). An open approach to the emotional support of fatally ill children, *Clinical Pediatrics*, 7: 274-280.

Katz, E. R. and Jay, S. M. (1984). Psychological aspects of cancer in children, adolescents, and their families, *Clinical Psychology Review*. 4:525–542.

Kelly, B., Raphael, B., Judd, F., Perdices, M., Kernutt, G., Burnett, P., Dunne, M., and Burrows, G. (1998). Suicidal Ideation, suicide attempts, and HIV infection, *Psychosomatics*, 39:405-415.

Kilbourne, A. M., Justice, A. C., Rabneck, L., Rodriguez-Barradas, M., Weissman, S. (2001). General medical and psychiatric co-morbidity among HIV-infected in the post-HAART era, *Journal of Clinical Epidemiology*, 54 Supplement 1:S22-8.

King, G., Delaronde, S., Dinoi, R , and Forsberg, A. D. (1996). Substance use, coping and safer sex practices among adolescents with haemophilia and Human Immunodeficiency Virus, *Journal of Adolescent Health* 18(6):435- 441.

Kliewer, K. and Lewis, H., (1995). Family influences on coping processes in children and adolescents with sickle cell disease, *Journal of Paediatric Psychology*, 204:511-525.

Knight, A., Aggleton, P., Candappa, M. (1999). *Social Care Services for Children and Families Affected by HIV in London: A review*. Institute of Education, Thomas Coram Unit, London.

Kubler-Ross, E. (1969). *On Death and Dying*, Springer, Macmillan, New York.

Kubler-Ross, E. (1983). *On Children and Death*, Macmillan, New York.

Kubler-Ross, E. (1987). *AIDS: the Ultimate Challenge*, Macmillan, New York.

Kyngas, H., Mikkonen, R., Nousiainen, E. M., Ryttilähti, M., Vaattovaara, R., Jamsa, T. (2001). Coping with the onset of cancer: coping strategies and resources of young people with cancer, *European Journal of Cancer Care*, 10:6-11.

Lam , P. K., Naar-King, S., Wright, K. (2007). Social Support and Disclosure as Predictors of Mental Health in HIV Positive Youth, *AIDS Patient Care and STDs*, Vol. 21, No.1.

Landau, G. and York, A. (2004). Keeping and disclosing a secret among people with HIV in Israel, *Health Social Work*, 29, 116-126.

Lansdown, G. (1994). *Children's Rights in Children's Childhoods: Observed and Experienced*, Routledge.

Lau, R. R., Quadrel, M. J., Harman, K. A. (1990). Development and Change of Young Adults' Preventive Health Beliefs and Behavior: Influence from Parents and Peers, *Journal of Health and Behavior*, Vol. 31, No.3: 240-259.

Lee, M., Rotherham-Borus, M. J., O'Hara, P. (1999). Disclosure of Serostatus among Youth Living with HIV, *AIDS and Behaviour*, Vol.3, No.1:33-40.

Lee, M. B. and Rotherham-Borus, M. J. (2002). Parents' disclosure of HIV to their children, *AIDS*, Vol. 16, Issue 16: 2201-2207.

Lee, R.M. (1993). *Doing Research on Sensitive Topics*, Sage, London.

Lee, R. S. (2002). Internalized Stigma Among People Living with HIV/AIDS, *AIDS and Behavior*, Vol. 6. No. 4:309-319.

- Lentine, D. A. (2000). HIV Related Knowledge and Stigma – United States, *Morbidity and Mortality Weekly Report*, 49:1062-64.
- Lenton, S., Stallard, P., Lewis, M. (2001). Prevalence and morbidity associated with non-malignant, life-threatening conditions in childhood, *Child: Care, Health & Development*, 27(5):389-398.
- Lesch, A., Swartz, L., Kagee, A., Moodley, K., Kafaar, Z., Myer, L., Cotton, M. (2007). Paediatric HIV/AIDS disclosure: towards a developmental and process-orientated approach, *AIDS Care*, 19(6):811-816.
- Lester, P., Chesney, M., Cooke, M. (2002a). Diagnostic disclosure to HIV infected children: how parents decide when and what to tell, *Clinical Child Psychology and Psychiatry*, 7:85-99.
- Lester, P., Chesney, M., Cooke, M., Weiss, R., Whalley, P., Perez, B., Glidden, D., Petru, A., Dorenbaum, A., Wara, D. (2002b). When the Time Comes To Talk About HIV: Factors Associated With Diagnostic Disclosure and Emotional Distress in HIV-Infected Children, *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 31(3):309-317.
- Letendre, S. L., Ellis, R. E., Overall, I., Ances, B., Bharti, A., McCutchan, J. A. (2009). Neurologic Complications of HIV Disease and Their Treatment, International AIDS Society, Topics in HIV Medicine, Conference Highlights – *Neurological Complications Vol. 17, Issue 2*.
- Letherby, G. (2003). *Feminist Research in Theory and Practice*, Buckingham, Open University Press.

Letteney, S. L. and La Park, H. H. (2004). Deconstructing Stigma: perceptions of HIV seropositive mothers and their disclosure to children, *Social Work in Health Care*, 38(3): 105-123.

Lewis, E. (2001). *Afraid To Say*, National Children's Bureau, London.

Lichtenstein, B., Laska, M. K., Clair, J.M. (2002). Chronic sorrow in the HIV positive patient: Issues of race, gender and social support, *AIDS Patient Care and STDs* 2002; 16(1):27-38.

Lightfoot, M., Rotherham-Borus, M. J., Milburn, N. G., Swendeman, D. (2005). Prevention for HIV Seropositive Persons: Successive Approximation toward a New Identity, *Behavior Modification*, Vol. 29, No. 2, 227-255.

Link, B. G. and Phelan, J.C. (2001). Conceptualising Stigma, *Annual Review of Sociology*, 27, 363-385.

Lipson M. (1993). What do you say to a child with AIDS? *The Hastings Centre Report* Vol. 23(2):6–12.

Lipson M. (1994). Disclosure of diagnosis to children with human immunodeficiency virus or acquired immunodeficiency syndrome, *Journal of Developmental Behavioral Pediatrics*, 15(3):S61–65.

Lolekha, R., Chanthavanich, P., Limkittikul, K., Luangxay, K., Chotpitayasunodh, T., Newman, C. J. (2004). Pain: a common symptom in human immunodeficiency virus infected Thai children, *Acta Paediatrica* Vol. 93 No. 7:891-898, Taylor and Francis.

Luchetta, T.(1999). Relationships between Homophobia, HIV/AIDS Stigma, and HIV/AIDS Knowledge. In Pardie, L. and Luchetta, T. (Eds.), *The construction of attitudes towards lesbian and gay men*, 1-19, Routledge.

Lupton, D. (1994). *Moral threats and dangerous desires: AIDS in the news media*, London, Taylor and Francis.

Lupton, D. and Tulloch, J. (1998). The Adolescent 'Unfinished Body', Reflexivity and HIV/AIDS, *Risk, Body and Society*, Vol. 4, No. 2, 19-34.

Lupton, D. (1999). Archetypes of infection: people with HIV/AIDS in the Australian press in the mid 1990's, *Sociology of Health & Illness*, Vol. 21, No. 1, 37-53.

Lwin, R, and Melvin, D, (2001). Annotation: Paediatric HIV Infection, *Journal of Child Psychiatry and Psychiatry*,42,4,427-38.

Lyon, M. and D'Angelo, L. (2006). *Teenagers, HIV and AIDS: Insights from Youths Living with the Virus*, Praeger Publishers, Connecticut.

MacDonald, R. and Marsh, J. (2005), *Disconnected Youth? Growing Up in Britain's Poor Neighbourhoods*, Basingstoke, Palgrave.

Mador, J. A. and Smith, D.H. (1989). The psychological adaptation of adolescents with cystic fibrosis: The review of the literature, *Journal of Adolescent Health Care*, 10(2,):136-142.

Madru, N. (2003). Stigma and HIV: Does the Social Response Affect the Natural Course of the Epidemic? *Journal of the Association of Nurses in AIDS Care*, Vol. 14. No. 5, 39-48.

- Malcolm, A., Aggleton, P., Bronfman, M. M., Galvao, J., Mane, P., Verrall, J. (1998). HIV – related stigmatisation and discrimination: Its forms and contexts, *Critical Public Health*, 8(4), 347-370.
- Maluccio, A. N. and Anderson, G. R. (2000). Future challenges and opportunities in child welfare, *Child Welfare*, 79(1):3-9.
- Mandlebaum, D. G., (1973), 'The Study of Life History: Ghandi', *Current Anthropology*, 14(3):177-93.
- Marellich, W. D. and Murphy, D. A. (2003). Effects of empowerment among HIV positive women on the patient-provider relationship, *AIDS Care* 15(4):475-481.
- Mason, T., Carlisle, C., Watkins, C., and Whitehead, E. (Eds.), (2001). *Stigma and Social Exclusion in Healthcare*, Routledge, London.
- Masson, J. (2004). *Doing Research with Children and Young People*, Sage, London.
- Mathieson, C, M. and Stam, H. J. (1995). Renegotiating identity: cancer narratives, *Sociology of Health & Illness* Vol. 17, Issues 3, 283-306.
- Mauthner, M., Birch, M., Jessop, J., Miller, T. (2002). *Ethics in Qualitative Research*, Sage, London.
- Mayfield Arnold, E., Rice, E., Flannery, D., Rotheram-Borus, M. J. (2008). HIV disclosure among adults living with HIV, *AIDS Care*, Vol. 20, Issue 1: 80-92.
- Maynard, D. W. and Clayman, S. E. (1991).The Diversity of Ethnomethodology, *Annual Review of Sociology*, Vol.17:385-418.

- McLeod, J. (2002), 'Working out intimacy: young people and friendship in an age of reflexivity', *Discourse: Studies in the Cultural Politics of Education*, Vol 23, No 2:221-26.
- McComsey, G. and Ethan, L. (2004), *Metabolic complications of HIV therapy in children: lipodystrophy, dyslipidemias, insulin resistance, bones disease, avascular necrosis, mitochondrial toxicity*, *AIDS* Vol.18(13):3.
- Mead, G. H. (1934). *Mind, Self and Society*, University of Chicago Press.
- Mellins, C. A. and Ehrhardt, A. A. (1994). Families affected by pediatric acquired immunodeficiency syndrome: sources of stress and coping. *Development Behaviour Pediatrics*, 15:54-60.
- Mellins, C. A., Brackis, C. , Dolezal, C., Richards, A., Nicholas, S. W., Abrams, E. J. (2002). Patterns of status disclosure to perinatally HIV infected children and subsequent mental health outcomes, *Clinical Child Psychology and Psychiatry*, Vol.7,No.1:101-114.
- Melvin, D. and Sheer, L. (1995). HIV infection in London children, *Child Care, Health and Development*, 21 (6), 35-42.
- Melvin, D. (2003). Children living with HIV: psychological concerns, *HIV Nursing*, 3:5-7.
- Melvin, D. (2007). Breaking the Silence, Reducing the Stigma, *Positive Nation*, 14.
- Meyer, I. H. (2003). Prejudice, Social Stress, and Mental Health Issues in Gay, Lesbian and Bisexual Populations: Conceptual Issues and Research Evidence, *Psychological Bulletin*, 129(5):674-697.

- Miah, J. (Ed.) (2004). *Talking with Young People and Families about Chronic Illness and Living with HIV*, National Children's Bureau, London.
- Michaud, P. A., Suris, J. C., Thomas, R. L., Kahlert, C., Rudin, C., Cheseaux, J. J. (2009). To Say or Not to Say: A Qualitative Study on the Disclosure of Their Condition by Human Immunodeficiency Virus-Positive Adolescents, *Journal of Adolescent Health*, 44: 356-362.
- Miles, K., Edwards, S., Clapson, M. (2004). Transitional from paediatric adult services: experiences of HIV positive adolescents, *AIDS Care*, 16(3), 305-14.
- Misha, F., Antle, B. J., Regehr, C., (2004). Tapping the Perspective of Children – Emerging Ethical Issues in Qualitative Research, *Qualitative Social Work*, Vol.3 (4):449-468.
- Mishel, M. H. (1990). Reconceptualization of the Uncertainty in Illness Theory, *Journal of Nursing Scholarship*, Vol. 22, Issue 4:256-262.
- Morrow, V. and Richards, M. (2002). The Ethics of Social Research with Children: An Overview, *Children and Society* Vol.10, No. 2:90-105.
- Morton, S. and Johnson, D. (1996). *Children and HIV: Supporting Children and their Families*, Children in Scotland, The Stationary Office Limited, Edinburgh.
- Murphy, D. A., Moscicki, A. B., Vermund, S. H., Muenz, L.R. (2000). Psychological Distress among HIV + Adolescents in the REACH Study: Effects of Life Stress, Social Support and Coping, *Journal of Adolescent Health*, 27:391-398.
- Murphy, D. A., Durako, S. J., Moscicki, A. B., Vermund, S. H., Ma, Y., Schwarz, D. F., Muenz, L. R. (2001). No change in health risk behaviours over time with HIV infected

adolescents in care: role of psychological distress, *Journal of Adolescent Health*, Vol. 29, Issue 3: 57-63.

Murphy, D. A., Roberts, K. J., Hoffman, D. (2002a). Stigma and Ostracism Associated with HIV/AIDS: Children Carrying the Secrets of Their Mother's HIV+ Serostatus, *Journal of Child and Family Studies*, Vol. 11, No. 2:191-202.

Murphy, D. A., Marelich, W., Hoffman, D. (2002b). A Longitudinal Study of the Impact on Young Children of Maternal HIV Serostatus, *Clinical Child Psychology and Psychiatry*, Vol. 7, No.1:55-70.

Murphy, D. A., Moussa Sarr, Durako, S. J, Moscicki, A. B., Wilson, C. M. and Muenz, L. R.(2003). Adolescent Medicine HIV/AIDS Research Network, Barriers to HAART Adherence Among Human Immunodeficiency Virus-Infected Adolescents, *Archives of Pediatrics and Adolescent Medicine*, Vol. 157, No 3: 249-255.

Murphy, J. S. (1995). *The constructed body: AIDS, reproductive technology and ethics*, Suny Press.

Naar-King, S., Templin, T., Wright, K., Frey, M., Parsons, J.T., Lam, P. (2006). Psychosocial Factors and Medication in HIV Positive Youth, *AIDS Patient Care and STDs*, Vol. 20, Number 1: 44-47.

Nagler, S. F., Adnopo, J., Forsyth, B.W.C. (1995). Uncertainty, stigma and secrecy: psychological aspects of AIDS for children and adolescents. In Geballe S., Gruendel, J. and Andiman, W., (Eds.), *Forgotten children of the AIDS epidemic*. 71-82, New Haven: Yale University Press.

NAM, National AIDS Manual Publication (2009). *Aidsmap*, September 9th.

NAT, National AIDS Trust (2009).Guidelines for Reporting HIV: Supplementary Information.

NAT, National AIDS Trust (2006). *Dispersal of Asylum Seekers Living with HIV*. London.

New. M., Lee, S., Pao, M. (2003). *Prevalence of mental health in pediatric HIV: a family perspective*, Presented at the NIMH Conference on the Role of Families in Preventing and Adapting to HIV/AIDS; Washington, DC.

Nöstlinger, C., Jonckheer, T., De Belder, E., Van Wijngaerden, E., Wylock, C., Pelgrom, J., Colebunders, R. (2004). Families affected by HIV: parents' and childrens' characteristics and disclosure to the children, *AIDS CARE*, Vol.16 No.5:641-648.

Nöstlinger, C., Bartoli, G., Gordillo, V., Roberfroid, D., and Colebunders, R. (2006). Children and adolescents living with HIV positive parents: emotional and behavioural problems, *Vulnerable Children and Youth Studies*, Vol. 1,Issue 1: 29-43.

Nusbaum, M.R.H., Hamilton, C., Lenahan, P. (2003). Chronic illness and sexual functioning, *American Family Physician*, 67 (2), 347-354.

Ogden, J. and Nyblade, L. (2005). *Common at it's Core: HIV Related Stigma Across Contexts*, International Centre for Research on Women (ICRW) Publication.

Olson, D. H. (1977). Insider's and Outsider's Views of Relationships: Research Studies. In Levinger, G. K. and Raush, H. L., (Eds.), (1977). *Close Relationship: Perspectives on the Meaning of Intimacy*, University of Massachusetts Press.

Ostrom, R. A., Serovich, J. M., Lim, J. Y., Mason, T. L. (2006). The role of stigma in reasons for HIV disclosure and non-disclosure to children, *AIDS Care*, 18(1):60-65.

Oxford English Dictionary. (2005). Oxford University Press.

Pachankis, J.E. (2007). The psychological implications of concealing a stigma: A cognitive –affective-behaviour model, *Psychological Bulletin* Vol.133(2):328-345.

Pantzou, P., Tselepi, C., Metallinou, O., Agrafiotis, D. (1998). Constraints and modes of adaptation of HIV - carriers in everyday life. *Working paper for synthesis session 12, Second European Conference on Methods and Results of Social and Behavioural Research on AIDS*, Paris.

Pao, M., Lyon, M., D'Angelo, L. J., Schuman, W. B., Tipnis, T., Mrazek, D. A. (2000). Psychiatric diagnoses in adolescents seropositive for the human immunodeficiency virus, *Archives of Pediatric Adolescent Medicine* 154(3) 240-44.

Parker, R. and Aggleton, P. (2003). HIV and AIDS related Stigma and Discrimination: A Conceptual Framework and Implications for Action, *Social Science and Medicine*, 57(1):15-24.

Pennebaker, J. (1985). Traumatic experience and psychosomatic disease: exploring roles of behavioural inhibition obsession and confiding, *Canadian Psychology* , 26:82-95.

Petrak, J. A., Doyle, A. M., Smith, A., Skinner, C., Hedge, B. (2001). Factors associated with self-disclosure of HIV sero-status to significant others, *British Journal of Health Psychology*, 6, 69-79.

- Petty, M. S. (2005). Social Responses to HIV: Fearing the Outlaw, *Sexuality Research and Social Policy: Journal of NSRC*, Vol. 2, No. 2: 76-88
- Pierret, J., (2000). Everyday life with AIDS/HIV: surveys in the social sciences, *Social Science and Medicine* 50:1589-1598.
- Pipe, M. E. and Goodman, G. S. (1991). Elements of secrecy: Implications for children's testimony, *Behavioural Sciences and the Law*, Vol.91, Issue 1: 33-41.
- Plank, E. N. (1964) Death on a children's ward, *Medical Times*, 92:638-644.
- Plattner, I. E. and Meiring, N. (2006). Living with HIV: the psychological relevance of meaning making, *AIDS Care* 2006; 18(3):241-245.
- Potter, J., and Hepburn, A. (2005). Qualitative interviews in psychology: problems and possibilities, *Qualitative Research in Psychology* 2(4): 281-307.
- Pound, P., Gompertz, P., Ebrahim, S. (1998). Illness in the context of older age: the case of stroke, *Sociology of Health & Illness*, Vol. 20, No. 4:489-506.
- Power, R. (1998).The role of qualitative research in HIV/AIDS, *AIDS*, 12:687-695.
- Rabkin, J. G., Ferrando, S. J., Lin, S. H., Sewell, M., McElhiney, M. (2000). Psychological Effects of HAART: A 2 year Study, *Psychosomatic Medicine*, 62:413-422.
- Radley, A. and Green, R. (1987). Illness as adjustment: a methodology and conceptual framework, *Sociology of Health & Illness* 9:179-207.

Ragins, B. R., Singh, R., Cornwell, J. M. (2007). Making the invisible visible: Fear and disclosure of sexual orientation at work, *Journal of Applied Psychology*, 92:1103-1118

Ragins, B.R, (2008). Disclosure Disconnects: Antecedents and Consequences of Disclosing Invisible Stigmas Across Life Domains, *Academy of Management Review*, Vol.33, No. 1:194-215.

Rhodes, T, and Cusick, L. (2000). Love and intimacy in relationship risk management: HIV positive people and their sexual partners, *Sociology of Health & Illness*, Vol. 22, No. 1:1-26.

Ridge, D., Williams, I., Anderson, J., Elford, J. (2007). Like a prayer: the role of spirituality and religion for people living with HIV in the UK, *Sociology of Health & Illness*, Vol.30, Issue 3, 413-428.

Riekert, K. A., Weiner, L., Battles, H. B. (1999). Prediction of psychological distress in school-age children with HIV, *Child Health Care*, 28:201-220.

Ritchie, J. and Lewis, J. (Eds.) (2003). *Qualitative Research Practice*. Sage, London.

Rosso, R., Biagio, A., Bassetti, M., Bassetti D. (2005). Treatment of HIV infection in children, *Reviews in Medical Microbiology*, 16(1):9-16.

Rotherham- Borus, M. J., Murphy, D. A., Kennedy, M., Stanton, A. and Kuklinski, M. (2001). Health and risk behaviours over time among youth living with HIV, *Journal of Adolescence*, 24:791-802.

Rotheram-Borus, M. J., Flannery, D., Rice, E., Lester, P. (2005). Families living with HIV, *AIDS Care*, 17(8):978-987.

Rubin, H.J. and Rubin, I.S. (2005). *Qualitative Interviewing –The Art of Hearing Data*, 2nd Edition, Sage, London.

Sacks, V. (1996). Women and AIDS: An analysis of media representations, *Social Science and Medicine*, Vol. 42, Issue 1: 59-73.

Saffer, J.B., Sanstone, P., Gentry J. (1979). The awesome burden on the child who must keep a family secret, *Child Psychiatry, Human Development*, 10:35-40.

Sanders, C., Donovan, J., Dieppe, P. (2002). The significance and consequences of having painful and disabled joints in older age: co-existing accounts of normal and disrupted biographies, *Sociology of Health & Illness*, Vol. 24, Issue 2:227-253.

Sartain, S. A., Clarke, C.L., Heyman, R. (2000) Hearing the voices of children with chronic illness, *Journal of Advanced Nursing*, Vol. 32, Issue 4:913-921.

Scambler, G. (1984). Perceiving and coping with stigmatizing illness. In Fitzpatrick, R., Hinton, J., Newman, S., Scambler, G. and Thompson, J. (Eds.), *The Experience of Illness*, Tavistock: London.

Scambler, G. and Hopkins, A. (1986). Being epileptic: coming to terms with stigma, *Sociology of Health and Illness*, Vol. 8, Issue 1:26-43.

Scambler, G. (2004). Re-framing Stigma: Felt and Enacted Stigma and Challenges to the Sociology of Chronic and Disabling Conditions, *Social Theory & Health*, Vol. 2, No. 1: 29-46.

Scharko, A.M. (2006). DSM psychiatric disorders in the context of pediatric HIV/AIDS, *AIDS Care*, 18(5):441-445.

Schneider, J. W. and Conrad, P. (1980). In The Closet with Illness: Epilepsy Stigma and Information Control, *Social Problems*, Vol. 28, No. 1: 32-44.

Schneider, J. W. and Conrad, P. (1985). *Having Epilepsy: The experience and control of illness*, Temple University Press, US.

Schur, H. V., Gamsu, D. S., Barley, V. B. (1999). The Young Person's perspective on Living and Coping with Diabetes, *Journal of Health Psychology*, 4:223-236.

Schwartzberg, S. S. (1993). Struggling for meaning: How HIV positive gay men make sense of AIDS, *Professional Psychology: Research and Practice*, Vol. 24(4), 483-490.

Scott, J. T., Harmsen, M., Pictor, M. J., Sowden, A. J. and Watt, I. (2003). Interventions for improving communication with children and adolescents about their cancer, *Cochrane Database System*,. (3):CD002969.

Serovich, J. M. and Mosack, K. E. (2003). Reasons for HIV disclosure or non-disclosure to casual sexual partners, *AIDS Education and Prevention*, 15: 70-80.

Shardland, M., Gibb, D. M. and Tudor-Williams, G. (2002). Advances in the prevention and treatment of paediatric HIV infection in the UK, *Archives of Diseases in Childhood*, 87:178-180.

Share, L.(1972). Family communication in the crisis of a child's fatal illness: a literature review and analysis, *Omega*, 3, 187-201.

- Share, L. (1980) *Caring Relationships: The Dying and the Bereaved*, Baywood Publishing Company.
- Sherman, B. F., Bonnanno, G. A., Wiener, L. S., Battles, H. B. (2000). When Children Tell Their Friends They Have AIDS: Possible Consequences for Psychological Well-Being and Disease Progression, *Psychosomatic Medicine*, 62:238-247.
- Sherr, L. (2006) Presentation at PPC (Positive Parents and Children) Conference at Southwark Cathedral (unpublished).
- Silverman, D. (2001). *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*, 2nd Edition, Sage, London.
- Silverman, D. (Eds.) (2004). *Qualitative Research: Theory, Method and Practice*. (2nd Edition), Sage, London.
- Silverman, D. (2005). *Doing Qualitative Research*, (2nd edition). Sage, London.
- Slavin, L. A., O'Malley, J. E., Koocher, G. P., Foster, D. J. (1982). Communication of the cancer diagnosis to pediatric patients: impact on long-term adjustment, *American Journal of Psychiatry*, 139(2):179–183.
- Smart, L. and Wegner, D.M. (1999). Covering up what can't be seen: Concealable stigma and mental control, *Journal of Personality and Social Psychology*, 77: 474-486.
- Smart, L., and Wegner, D. M. (2000). The hidden costs of hidden stigma. In Heatherton, T, Kleck, R., Hebl, M., and Hull, J. (Eds.) *The Social Psychology of Stigma* 220-242, New York: Guildford Press.

- Smith, R., Rossetto, K., and Peterson, B. L. (2008). A meta-analysis of disclosure of one's HIV positive status, stigma and social support, *AIDS Care*, Vol. 20, No. 10:1266-1275.
- Sontag, S. (1978). *Illness as Metaphor*. London: Penguin.
- Sontag, S. (1989) *AIDS and Its Metaphors*. London: Penguin.
- Spinetta, J. (1974). The dying child's awareness of death: A review, *Psychology Bulletin*, 81: 256-260.
- Spinetta J. J. and Maloney, L. J. (1978). The child with cancer: patterns of communication and denial, *Journal of Consultant Clinical Psychology*, 46(6):1540-1541.
- Squire, C, (1997). 4 AIDS Panic. In Usher, J. M. *Body Talk: the material and discursive regulation of sexuality, madness and reproduction*, Routledge.
- Stangor, C. and Crandall, C. S. (2000). Threat and the Social Construction of Stigma. In Heatherton, T. F., Kleck, R. E., Hebl, M. R., and Hull, J. G. (Eds.), *The Social Psychology of Stigma*, London, The Guildford Press.
- Stanley, B and Sieber, J. E. (Eds.) (1992). *Social Research on Children and Adolescents*, Newbury Park, CA, Sage Publication.
- Stebbins, R. (1970). Career: the subjective approach, *Sociological Quarterly*, 11:32-49.
- Steele, R.G. and Grauer, D. (2003). Adherence to Antiretroviral Therapy for Pediatric HIV Infection: Review of the Literature and Recommendations for Research, *Clinical Child and Family Psychological Review*, Vol. 6, No.1:17-30.

Stewart, J. L., (2003) 'Getting Used to It': Children Finding the Ordinary and Routine in the Uncertain Context of Cancer, *Qualitative Health Research*, Vol. 13 No. 3: 394-407.

Strauss, A. and Corbin, J. (1990). *Basics of Qualitative Research*, Thousand Oaks, CA: Sage.

Strauss, A. and Corbin, J. (1998a). Grounded Theory methodology: an overview. In Denzin, N. and Lincoln, Y. (Eds.), *Strategies of Qualitative Inquiry*, 158-183, Sage, London.

Strauss, A. L. and Corbin, J. M. (1998b). *Basics of qualitative research: Techniques and procedures for developing grounded theory*, Sage, London.

Stryker, S. and Burke, P. J. (2000). The Past, Present, and Future of an Identity Theory, *Social Psychology Quarterly*, Vol. 63, No. 4: 284-297.

Stuber, M. (2003). Posttraumatic stress responses in children with life-threatening illnesses, *Child and Adolescent Psychiatric Clinics of North America*, Vol. 12, Issue 2: 195-209.

Swann, W. B. Jr. (1983). Self-verification: Bringing social reality into harmony with the self. In Suls, J. and Greenwald, A. G. (Eds.), *Social psychological perspective on the self*, Vol.2: 33-66. Hillsdale, NJ: Erlbaum .

Swann, W. B. Jr. (1987). Identity negotiation: Where two roads meet. *Journal of Personality and Social Psychology*, 53: 1038-1051.

Swendeman, D., Rotherham-Borus, M. J., Comulada, M.S., Weiss, R., Ramos, M.E. (2006). Predictors of HIV related stigma among Young people Living with HIV, *Health Psychology*, 25(4): 501-509.

Squire, C. (1997). 4 AIDS Panic. In Usher, J. M. *Body Talk: the material and discursive regulation of sexuality, madness and reproduction*, Routledge.

Taylor, S. (2001). Places I remember: Women's talk about residence and other relationships to place, *Auto/Biography*, 9:33-40.

Taylor, S. and Littleton, K. (2006). Biographies in talk: A narrative –discursive research approach, *Qualitative Sociology Review*, Vol.11, Issue 1.

Tewksbury, R. and McGaughey, D. (1998). Identities and Identity Transformations among Persons with HIV Disease, *International Journal of Sexuality and Gender Studies*, Vol. 3, No. 3: 213-232.

Thomson, R., Bell, R., Holland, J., Henderson, S., McGrellis, S. and Sharpe, S. (2002), Critical Moments: Choice, Chance and Opportunity in Young Peoples' Narratives of Transition, *Sociology*, 36:335.

Thomson, R., Holland, J., McGrellis, S., Bell, R., Henderson, S. and Sharpe, S. (2004), Inventing adulthoods: a biographical approach to understanding citizenship, *The Sociological Review*.

Thomson, R. (2007) A biographical approach, in Kehily, M. J., *Understanding Youth: perspectives, identities and practices*, The Open University, Sage Publications.

Thorne, C., Newell, M-L., Peckham, C. S. (2000). Disclosure of diagnosis and planning for the future in HIV affected families in Europe *Child: Care, Health and Development*, Vol.26, Issue 1:29.

Thorne, C., Newell, M-L., Botet, F. A., Bohlin, A. B., Ferrazin, A., Giaquinto, C., Gomez, I.de J., Mok, J.Y.Q., Mur, A. and Peltier, A. (2002). Older Children and Adolescents Surviving With Vertically Acquired HIV Infection, *Journal of Acquired Immune Deficiency Syndromes*, 29:396-401.

Timmermans, S. (1994). Dying of awareness: the theory of awareness contexts revisited, *Sociology of Health & Illness*, Vol.16. No. 3:322-338.

UNAIDS (2002). A conceptual framework and basis for action: HIV/AIDS stigma and discrimination (World AIDS Campaign 2002-2003), United Nations: Geneva

UNAIDS (2008).Report on the Global Epidemic, accessed on 26.09.09.
http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp

Valencia, L.S. and Cromer, B. A. (2000).Sexual Activity and Other high Risk Behaviour in Adolescents with Chronic Illness: A Review, *Journal of Pediatric Adolescent Gynaecology*, 13:53-64.

Van Dongen-Melman, J.E.W.M. and Sanders-Woudstra, J.A.R. (1986). Psychosocial Aspects of Childhood Cancer: A Review of the Literature, *Journal of Child Psychology and Psychiatry*, Vol. 27, No. 2:145-180.

Van Dyke, R. B., Lee, S., Johnson, G. M., Wiznia, A., Mohan, K., Stanley, K., Morse, E. V., Krogstad, P. A., Nachman, S. (2002). Reported adherence as a determinant of

response to highly active antiretroviral therapy in children who have human immunodeficiency virus infection, *Pediatrics* 109 (4) 61.

Varas Diaz , N., Toro-Alfonson, J., Serrano-Garcia, I. (2005). My Body, My Stigma: Body Interpretations in a Sample of People Living with HIV/AIDS in Puerto Rico, *The Qualitative Report*, Vol.10. No. 1: 122-142.

Veinot, T. C., Flicker, S. E., Skinner, A. H., McClelland, A., Saulnier, P., Read, S. E., Goldberg, E. (2006). 'Supposed to make you better but it doesn't really': HIV Positive youths perceptions of HIV treatment, *Journal of Adolescent Health* 38: 261- 267.

Waechter, E. (1973). Children's awareness of fatal illness, *American Journal of Nursing*, 71:1168–1172.

Walker, S. A., Doerholt, K., Gibb M. (2004). Response to highly active antiretroviral therapy varies with age: the UK and Ireland Collaborative HIV Paediatric Study, *AIDS*, Vol. 18, Issue 14:1915-1924.

Warwick, I., Brownfoot, J., Whitty, G. (1999). *Empower, Enable and Engage: Pupils and Families Living with HIV*, Luxembourg: Office for Official Publications.

Waugh, S. (2003). Parental views on disclosure of diagnosis to their HIV positive children, *AIDS Care*, Vol.15, No. 2:169-176.

Webster, C., Simpson, D., MacDonald, R., Abbas, A., Cieslik, M., Shildrick, T. and Simpson, M. (2004), *Poor Transitions: Young Adults and Social Exclusion*, Bristol, Polity Press.

- Weigert, A. J. (1986). The Social Production of Identity: Metatheoretical Foundations, *The Sociological Quarterly*, Vol. 27, No. 2:165-183.
- Weitz, R. (1990). Living with the stigma of AIDS. *Qualitative Health Research*, 7(1):75-97.
- Whetten, K., Reif, S., Whetten, R., Murphy-McMillan, L. K. (2008). Trauma, Mental Health, Distrust, and Stigma Among HIV-Positive Persons: Implications for Effective Care, *Psychosomatic Medicine*, 70:531-538.
- Wiener, B., Perry, R. P., Magnusson, J. (1988). An Attributional Analysis of Reactions to Stigma, *Journal of Personality and Social Psychology*, 55(5):738-748.
- Wiener, L. S., Battles, H. B., Heilman, N., Sigelman, C., Pizzo, P. A. (1996). Factors associated with disclosure of diagnosis to children with HIV/AIDS, *Pediatric AIDS and HIV Infection*, 7:310-324.
- Wiener, L. S., Battles, H. B., Heilman, N. (2000). Public disclosure of a child's HIV infection: Impact on children and families, *AIDS Patient Care STDS*, 14:485-497.
- Wiener, L. S., and Battles, H. B. (2006). Untangling the web: A close look at diagnosis disclosure among HIV infected adolescents, *Journal of Adolescent Health*, 38: 307-309.
- Wiener, L. S., Battles, H. B., and Wood, L. V. (2007a). A Longitudinal Study of Adolescents with Perinatally or Transfusion Acquired HIV Infection: Sexual Knowledge, Risk Reduction Self-efficacy and Sexual Behavior, *AIDS Behavior*, 11:471-478.
- Wiener, L., Mellins, C. A., Marhefka, S., Battles, H.B. (2007b). Disclosure of an HIV Diagnosis to Children: History, Current Research, and Future Directions, *Journal of Developmental Behavioural Pediatrics* 28:155-166.

Wiles, R., Heath S., Crow, G., and Charles, V. (2005). Informed Consent in Social Research: A Literature Review, ESRC National Centre for Research Methods, *NCRM Methods Review Papers /001*, University of Southampton.

Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? *Sociology of Health & Illness*, Vol. 22, Issue 1:40-67.

Wilson, S. (2007). 'When you have children, you're obliged to live': motherhood, chronic illness and biographical disruption, *Sociology of Health & Illness*, 29:610-626.

Wilson, T. (1997). *EnGendering AIDS: deconstructing sex, text and epidemic*, Sage.

Wood, S. (2009). The impact of AIDS diagnoses on long-term neurocognitive and psychiatric outcomes of surviving adolescents with perinatally acquired HIV, *AIDS*, 23:1859-1865.

Woodgate, R. (1998). Adolescents' perspectives of chronic illness: "It's hard", *Journal of Pediatrics Nursing*, 13: 210-223.

Yoshida, K. K. (1993). Reshaping of self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury, *Sociology of Health & Illness*, Vol. 15, No. 2: 217-245.

Young, B., Dixon-Woods, M., Windridge, K.C., Heney, D. (2003). Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents, *British Medical Journal*, 326:305.

Zea, M. C., Reisen, C. A., Poppen, P. J., Bianchi, F. T., Echeverry, J. J. (2005).

Disclosure of HIV Status and Psychological Well-Being among Latino Gay and Bisexual Men, *AIDS and Behavior*, Vol. 9, No. 1:15-26.

APPENDIX 1

HUMAN PARTICIPANTS AND MATERIALS ETHICS COMMITTEE

FROM: John Oates, Chair, HPMEC **Email:** j.m.oates@open.ac.uk

To: Judith Dorrell, Faculty of Health and Social Care **TEL:** 52395

CC: **DATE:** 2 January 2007

SUBJECT: **Ethics application:** Being Young and HIVRef: HPMEC/07/#247/1
Positive – The experiences of young people
living with HIV since birth.

This memorandum is to confirm that the research protocol for the above-named research project, as submitted on 28/11/2006, and as subsequently revised in email correspondence, is approved by the Open University Human Participants and Materials Ethics Committee.

At the conclusion of your project, by the date that you stated in your application, the Committee would like to receive a summary report on the progress of this project, any ethical issues that have arisen and how they have been dealt with.

John Oates

Chair, OU HPMEC

Approval letter from St Mary's

From: St Marys Rec [mailto:stmarys.rec@corec.org.uk]
Sent: Fri 23/02/2007 16:04
To: 'J.Dorrell'
Subject: 07 3 Approval letter

signed letter in the post - there is a note on the database about your meeting with Graham, Barrie, myself with Diane Melvin present.

St Mary's REC
2nd Floor A Block
50 Eastbourne Terrace
Paddington
London
W2 6LG

Telephone: 020 7725 2846
Facsimile: 020 7725 5317

23 February 2007

Ms J Dorrell
PhD Research Student
The Open University.
Faculty of Health and Social Care
Walton Hall
Milton Keynes
MK7 6AA

Dear Ms Dorrell

Full title of study: Being Young and HIV Positive: The experiences of young people infected with HIV since birth.

REC reference number: 07/Q0403/3

Thank you for your letter of 15 February 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman and Graham Taylor.

Confirmation of ethical opinion:

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the

attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document - Version - Date

Application 5.2 31 January 2007

Investigator CV 1 20 December 2006

Protocol 1 20 December 2006

Protocol 2 14 February 2007 Covering Letter n/a 15 February 2007

Peer Review 1 20 December 2006

Compensation Arrangements 1 20 December 2006

Interview Schedules/Topic Guides 2 14 February 2007

Interview Schedules/Topic Guides 1 20 December 2006

Letter of invitation to participant 1 20 December 2006

Participant Information Sheet 2 12 February 2007

Participant Information Sheet: Parents/Legal guardian 2 12 February 2007

Participant Consent Form: young people under 16 years 1 20 December 2006

Participant Consent Form: parent/legal guardian 1 20 December 2006

Participant Consent Form: Young People over 16 yrs 1 20 December 2006 Response to Request for Further Information n/a 15 February 2007

Contacts for brothers/sisters 1 29 January 2007

Contacts for parents/legal 1 29 January 2007

Letter of Invitation for potential participants 1 20 December 2006

Funding letter Dr Katz OU 20 December 2006

Support statement n/a 13 February 2007

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q0403/3

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Barrie Newton
Chairman

Email: stmarys.rec@corec.org.uk

Enclosures:

Standard approval conditions
Site approval form
Copy to:Dr Jeanne Katz
The Open University
Faculty of Health and Social Care
Walton Hall, Milton Keynes
MK7 6AA

St Mary's REC

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number: 07/Q0403/3

Issue number:0

Date of issue: 23 February 2007

Chief Investigator:Ms J Dorrell

Full title of study: Being Young and HIV Positive: The experiences of young people infected with HIV since birth.

This study was given a favourable ethical opinion by St Mary's REC on 23 February 2007.

The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.

Principal Investigator Judith Dorrell
Post
Research site St Marys
Site assessor St Marys REC
Date of favourable opinion for this site 23.2.7
Notes (1)
Approved by the Chair on behalf of the REC:

..... (Signature of Co-ordinator)

Rosalind Cooke

APPENDIX 2

Participant Information sheet

Being Young and HIV Positive: the experiences of young people living with HIV since birth.

Invitation

You are being invited to take part in a research study which plans to look at the experiences of young people with HIV. Before you decide if you want to take part it's important to understand what it's about and what it will involve for you. So please read this leaflet carefully. Talk about it with your family, doctors or nurses and ask questions if you want to.

Thank you for reading this.

1. What is this study about and why are we doing it?

I am interested in finding out what it is like for you living with HIV. I want to hear your views and opinions and give you an opportunity to share your story. I want to know how living with HIV has affected your life, your relationships, family, health, education and plans for your future. I think it is important to hear your experiences of what it means to you.

The study will help us understand more about HIV so we can learn from what you tell us, to change things or do things in a different way. I hope what we learn from this research will help other younger children as they grow up with HIV. It may also help people working with you to understand your point of view better.

2. Why have I been chosen?

You have been chosen because you have HIV and as a young person you have had the experience of living with HIV for some time. I hope to interview 25 young people with HIV from this hospital.

3. Do I have to take part?

No! It's really up to you to decide if you want to take part or not. If you are under 16 years old you will need your parent(s) or legal guardian(s) to give their permission as well for you to take part in the study. If you do decide to take part you will be asked to sign a consent form.

4. What will happen to me if I take part?

Taking part would mean you will be interviewed by me for about one hour and the interview will be tape recorded. I will interview you on your own in the hospital clinic when you come for your usual appointment. I will ask you some questions about how HIV has affected different parts of your life such as family, friends and relationships. I will ask you how you feel about things.

5. What are the possible benefits of taking part?

I hope that the experience of taking part will be interesting and a rewarding one for you as it is an opportunity to tell your story and share your views and this can be a good experience. I can't promise the study will help you, but it may help younger children growing up with HIV get support and care from people who will understand a bit better about what it has been like for you.

6. What are the possible disadvantages of taking part?

In the interview I will be asking you questions about yourself and your experiences of living with HIV. For some, these questions may be upsetting.

7. What if I change my mind?

If you change your mind about taking part in the study you can leave at any time without having to give a reason and this will not affect your medical treatment or care.

8. What about confidentiality?

All information that is collected during this study will be kept strictly confidential. All the interviews will be stored securely at The Open University. The taped interviews will be kept for 5 years and then will be destroyed. If you ask for your interview recording to be destroyed before the end of the study I will do this after the results have been written up. Any personal information about you (such as your name and address) will be removed so you cannot be recognised from it.

I will make sure that you cannot be recognised in my report (thesis). I will not use real names and everyone who takes part will be given a pseudonym, (false name).

9. Child Protection

Everything you tell me will remain private, unless you tell me something that leads me to believe that you or someone else is at risk of harm. In this unusual situation I would pass this information on to someone who would be able to help. Ideally I would do this with your agreement, and I would always let you know that I am taking such action. I will follow the child protection procedures of the hospital. In order to protect young people and do this research I have had a Criminal Records Bureau check.

10. What happens to the information?

The results of this study will be used in my PhD report and may be published in books and academic journals. I will send a summary of my study to everyone who takes part at the end of the project.

11. Who has checked the study?

Before any study like this can go ahead it needs to be checked by an Ethics Committee. They make sure that the research is OK to do. This study has been checked by the Open University Human Participants and Material Ethics Committee and the NHS Ethics committee.

12. Who to contact for more information or you have any questions

You can contact

Judith Dorrell in the Faculty of Health and Social Care

Tel: 01908 654926 Email: j.dorrell@open.ac.uk

Dr Jeanne Katz, Director of Post-Graduate Studies

Faculty of Health and Social Care

Tel: 01908 654233 Email: J.T.Katz@open.ac.uk

Thank you for reading this

Information Sheet for Parent(s)/Legal Guardian(s)

Being Young and HIV Positive: The experiences of young people living with HIV since birth.

1.Invitation

Your child is being asked to take part in a research project to look at the experiences of young people living with HIV. This research is part of a PhD study.

2.What is this study about and why are we doing it?

I am interested in finding out how HIV affects the lives of young people who have lived with it all their lives. I want to give young people an opportunity to share their stories about their experiences and to hear their views. I am interested in how living with HIV affects daily life, relationships, family, health, education and plans for the future. How does HIV affect relationships not only with family but friends and others? I think it is important to listen to young people who have experience of what it means to live with a diagnosis of HIV; I am interested in finding out what helps young people adjust to having HIV, what support has been useful and what support they would have liked to have been there.

The study will help us understand more about HIV so we can learn from what young people tell us, to change things or think about helping young people in a different way. I hope what we learn from this research may help other younger children as they grow up with HIV. It may also help people working with young people with HIV to understand from a young person's point of view.

3.Why has my child been chosen?

Your child has been chosen because they are living with HIV and are now becoming young people who have lived with HIV all of their lives. This study will involve interviewing 25 young people.

4.Does my child have to take part?

No. It is up to you and your child to decide whether or not to take part. You are both free to withdraw from the research at any time without giving a reason. If you do decide to give permission for them to take part you will be asked to sign a consent form. Your child will also be asked to sign a consent form if they agree to take part.

5.What does my child have to do if we agree to take part?

Your child will be interviewed in the hospital clinic on their own for about 1 hour. They will be asked questions about what it is like to live with HIV and about their experiences. This will mean talking about how they feel about issues. They would only be interviewed once and the interview will be tape recorded.

6. What are the possible benefits of taking part?

I hope that the experience of taking part will be interesting and a rewarding one for your child as it is an opportunity for them to tell their story and share their views and opinions which, for many is a positive experience.

Knowing this study may be of use to others in a similar situation or to those working with young people, makes some people feel they are making a valuable contribution.

7. What are the possible disadvantages of taking part?

This study will ask your child about their experiences of living with HIV. Some of the issues we may discuss could be upsetting for some children.

8. What will happen if my child or I don't want to carry on with the research?

Your child can leave the study at anytime without having to give a reason and this will not affect their medical treatment or care. If your child decides to leave after being interviewed, their interview material will be destroyed. If your child requests that their data be destroyed this will be done at the end of the study.

9. What about confidentiality? Will my child's taking part be kept confidential?

All information that is collected during this study will be kept strictly confidential. All interview material will be stored securely at The Open University. This material will be held for the length of the study and then destroyed. If your child requests their data to be destroyed before the end of the study this will be done once the results have been written up. Any information about your child will have their name and address removed so they cannot be recognised from it. In order to protect anonymity everyone who takes part will be given a pseudonym, (false name). No child will be able to be recognised in my report (thesis). We will not use their real name and we will change information that might identify your child to others who know them.

If your child discloses information leading us to believe that they or someone they know is at risk of harm, we have a responsibility to pass this information on to (a named person) in social services, ideally with their consent, but always with their knowledge. The child protection procedures of the hospital will be followed.

9.What happens to the information collected in this study?

The results of this study will be used in my PhD report and may be published in books or academic journals. All those who take part in the study will be sent a summary of the findings at the end of the project .

10.Who is organising and funding the research?

The Open University at Milton Keynes is supervising and funding this research through a PhD studentship.

11.Who has reviewed the study?

Before any research goes ahead it has to be approved by an ethics committee. This study has been reviewed and approved by the Open University Human Participants and Material Ethics Committee and by the NHS Ethics Committee*.

Contact Details:

You can contact

Judith Dorrell in the Faculty of Health and Social Care.

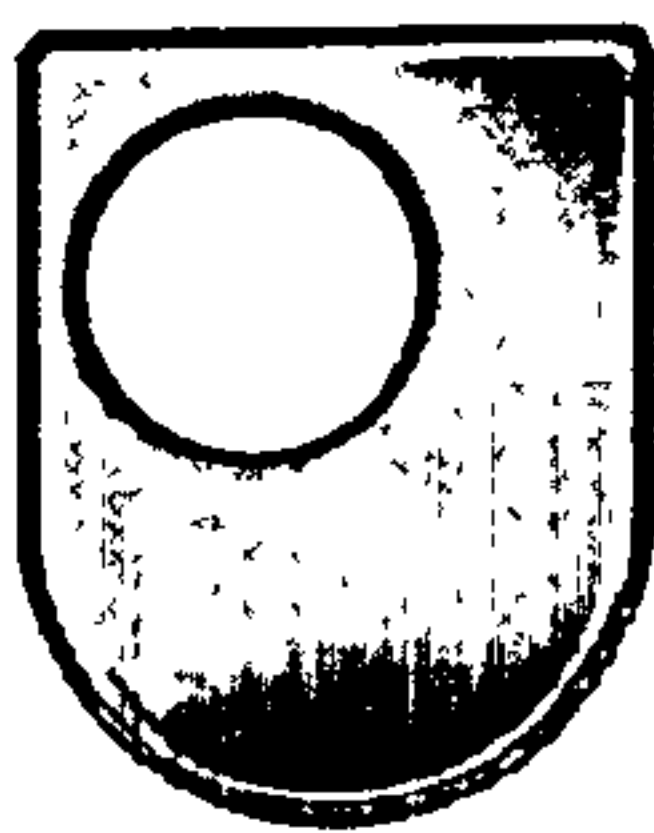
Tel: 01908 654926 Email: J.Dorrell@open.ac.uk

Dr Jeanne Katz, Director of Post-Graduate Studies

Faculty of Health and Social Care

Tel: 01908 654233 Email: J.T.Katz@open.ac.uk

Thank you for reading this information



PARENT/LEGAL GUARDIAN CONSENT FORM

Title of project: Being Young and HIV Positive: The experiences of young people infected with HIV since birth

Name of researcher: Judith Dorrell

Before I start the interview with your child/young person please read the statements below:

Please initial box

1. I confirm that I have read and understand the information sheet
☐ dated..... about this study. I have had the opportunity to ask questions and have had these answered satisfactorily.
2. I understand and agree that my child will be interviewed alone.
☐
3. I understand that my child has voluntarily agreed to take part in this study but if they want to leave the study at any time they are free to do so without giving any reason and this will not affect their medical treatment or care.
☐
4. I understand that everything my child says in the interview is confidential, their identity will be anonymous and there is no possibility that they or their family can be identified.
☐

5. I agree that my child's contribution will be securely stored at the Open University for the length of the study, with access only to the interviewer.

☐

6. I give Judith Dorrell permission to anonymously quote my child's words used in their interview for her PhD report and publications.

☐

9. I agree for my child to take part in this study.

☐

Name of Child

Name Parent/Guardian

Signature

Date

Researcher

Signature

Date

Contact for further information: Judith Dorrell on 01908 654233
j.dorrell@open.ac.uk

CONSENT FORM FOR YOUNG PEOPLE UNDER 16 YEARS

Title of the Project: Being Young and HIV Positive : The experiences of young people living with HIV since birth

Name of researcher: Judith Dorrell

Before we start the interview please read the statements below: Please initial box

1. I confirm I have read and understand the information sheet about this study and have had the opportunity to ask questions and have answers that I am happy with.
☐
2. I understand that no one is making me take part in this study and I can leave at any time and do not need to give a reason and this will not affect my medical treatment or care.
☐
3. I understand that direct quotations may be taken from my interview; however, I will not be able to be identified from these quotes. I give my permission for direct quotes to be used
☐
4. I agree to take part in this study
☐
5. I know my parents/legal guardian know about this study
☐

Name of participant

Signature

Date

Researcher

Signature

Date

Contact for further information - Judith Dorrell: 01908 654233
j.dorrell@open.ac.uk

Thank you for taking part in this study

CONSENT FORM FOR YOUNG PEOPLE OVER 16 YEARS

Title of project: Being Young and HIV Positive - The experiences of young people infected with HIV since birth

Name of researcher: Judith Dorrell

Before we start the interview please read the statements below: Please initial box

1. I confirm that I have read and understood the information sheet I was given about this study and I have had the opportunity to ask questions and have had these answered satisfactorily.

☐

2. I understand that no one is making me take part in this study and I can leave at any time without giving a reason and this will not affect my medical treatment or care.

☐

3. I understand that direct quotations may be taken from my interview; however I will not be able to be identified from these quotes. I give my permission for direct quotes to be used.

☐

4. I agree to take part in this study.

☐

Name of Participant
Date

Signature

Researcher
Date

Signature

Contact for Further information : Judith Dorrell 01908 654926
j.dorrell@open.ac.uk

Thank you for taking part in this study

APPENDIX 3

321

QUESTIONS FOR INTERVIEWS

Topic Areas:

Family

Friends

HIV

School/work

Relationships

Support

Future

Questions:

1. Tell me about your school/college/work
2. Tell me about your friends/family
3. How would you describe yourself?
4. Tell me about how you see your future
5. How do you feel HIV affects your life?
6. Tell me about the things that are not so good or make you unhappy
7. Tell me about the things that are good in your life/makes you happy

Characteristics of Participants

1. Ben is seventeen and is British. His father died from HIV when he was seven. Ben's parents were infected with HIV through intravenous drug use. He lives on his own in his mother's flat in northern England. His mother lives abroad and visits him regularly. Ben is at Further Education College studying animation and currently has a girlfriend.
2. Paul is twenty-four and was born in the UK, his parents came from Zambia. His parents are both dead. His mother and older brother died from HIV. Paul was five when his mother died and thirteen when his brother died. His aunt also died from HIV. He and his brother were cared for by social services. He currently lives on his own in London and has a child. He dropped out of college and works in the voluntary sector.
3. Asha is twenty-three and was born in Zambia and came to the UK when nine. Her mother died from HIV in Zambia when she was nine. She was cared for by her father and step-mother, she has step brothers and one step-sister that are not infected with HIV. She currently lives on her own but has contact with her father. She has a degree and wants to pursue a career in youth work.
4. Mark is eighteen and was born in the UK; his parents are both from Uganda. He lives in London with his mother and grandmother who brought him up. He has no contact with his father. HIV has affected his eyesight and consequently he has very poor vision. He currently works as a waiter, but wants to work in the music industry.

5. Neema is seventeen and was born in the UK to Ugandan parents. She has two brothers, one died from HIV when he was two years old and the other is not infected. Her aunt also died from HIV. Neema's parents are separated and she lives with her mother and brother in the South West of England. She plans to go to University and wants to work in health and social care.
6. Denisha died in 2009 at eighteen. She was born in Ghana and came to the UK when two. Her mother died from HIV in Ghana and her father died in the UK when she was twelve. She was brought up by her step mother and lived with her sister in London.
7. Amy is eighteen and was born in the UK. Her father died in Zambia from HIV. She was raised by her grandparents on the South coast as her mother was unable to care for her. Her mother was on drugs and supported Amy by selling sex. Her grandmother died when she was sixteen. She became a mother at 16 and lives with her boyfriend and is unemployed.
8. Alica is nineteen and was born in the UK, her mother is from Thailand and her Father is white British. Her parents are divorced and her younger sister, who is also HIV positive, lives with her father in the Midlands. Alica lives in London with her mother who has mental health problems. She works as a legal secretary.
9. Matthew is eighteen and was born in the UK, his mother is Kenyan and his father is from the UK. His mother died when he was two. He grew up in the Home Counties with his father and maternal aunt and is currently at university. He wants to study medicine.
10. Ruth is twenty and was born in Uganda to Ugandan parents. Her father and aunt died from HIV. She was three when she came to the UK and lived with her mother

and sister in London. She has nine other siblings. Her mother and two brothers are HIV positive. She plans to go to University but is currently unemployed.

11. Charlotte is nineteen and was born in the UK. Her parents died from HIV before she was five. Her father was Greek and her mother was from the UK. She lives with her maternal grandmother. She has very poor health but hopes to train as a social worker and work with children.

12. Jamelia is twenty and was born in Uganda to Ugandan parents. Her father, four aunts and two uncles have died from HIV. She came to the UK when she was four. She grew up in London with her mother. Her two brothers do not have HIV. Jamelia is currently unemployed.

13. Elijah died in 2009. He was twenty. He was born in Zambia to Zambian parents who both died from HIV before he was five. Six uncles and aunts have died from HIV. He was brought to the UK by his maternal aunt and uncle when he was five and they raised him. His uncle is also HIV positive. He lived independently in London and loved music.

14. Samuel is nineteen and was born in Zambia to Zambian parents. He came to the UK when he was eight. His father died of HIV when Samuel was seven and his mother brought him to the UK with his brother. His brother is not HIV positive. He lives independently in a bed-sit as his mother has returned to Zambia. He is at college studying business studies and plans to return to Zambia.

15. Louisa is seventeen and was born in Uganda to Ugandan parents. Her father died from HIV when she was four. One aunt has died from HIV in the UK and one in Uganda. She came to the UK when she was two. She lives in London with her mother and step father who are both HIV positive. Her maternal aunt is also HIV

positive. She has one sister, six half sisters and four half brothers. She is currently doing her A' levels at college.

16. Carmel is eighteen and died in 2009. She was born in Zambia to Zambian parents. Her mother died when she was four and had no knowledge of her father. Her brother died at seventeen and five aunts and three uncles died from HIV in Zambia. She came to the UK when she was three. She had five brothers and was raised by her grandmother who died in 2009. She wanted to work in performing arts.

17. Callum is eighteen and was born in Zimbabwe to Zimbabwean parents. He came to the UK when he was ten. He lives with his mother and brother in the Midlands area. His mother, father, brother and uncle are HIV positive. One aunt and uncle died from HIV. He is deaf as a result of the HIV virus and medication. His parents are divorced and he attends Art College and hopes to go to University to study art.

18. Joshua is twenty-two and was born in Uganda to Ugandan parents. His mother and father both died from HIV and several aunts and uncles have died from HIV. He came to the UK with his sister when he was eleven and they lived in bed and breakfast accommodation for some years, but he now lives in a flat on his own in the London area. He left school at sixteen and went onto college but failed the course and he is currently unemployed.

19. Jonas is sixteen and was born in the UK to Ugandan parents. He lives with his family in the Midlands. Both his parents and younger brother are HIV positive. He has problems with mobility due to spasticity in his legs which has required several operations. He is currently at school doing A levels.

20. Lakeesha is seventeen and was born in Djouboti. Her parents came to the UK when she was two. Her parents are divorced and she lives with her mother, brother and sister in London. She is currently at school and plans to go to university.
21. Elly is fifteen and was born in the UK. Her mother died from HIV when she was four. She lives with her father and stepmother in the Midlands. She has two half-sisters and is the only one infected in the family. She is currently at school.
22. Catriona is seventeen and was born and adopted in Romania. She lives in the north of England with her adopted parents. She has an older brother and sister who are married and have families. She is the only one infected in the family. She has been studying beauty therapy for two years at college. She has a boyfriend and plans to set up her own business.
23. Becka is seventeen and was born in Kenya, her mother is Kenyan and her father is from the UK. Her father brought her to the UK when she was two and since has had no contact with her mother. She lives in the north of England and has two older sisters and one half-brother. Her father has re-married and she is the only one infected with HIV in her family. She is currently at school doing A levels.
24. Jina is seventeen and was born in Zambia to Zambian parents. Her father died from HIV. Most of her extended family in Zambia have also died from HIV. She came to the UK when she was three and lives with her mother, step-father and three step-brothers on the South coast. She is currently at Further Education College studying nursing.
25. Rebecca is seventeen and was born in Zimbabwe to Zimbabwean parents. Her father died from HIV in Zimbabwe and many members of her extended family have

died from HIV. She came to join her mother in the UK when she was eleven. She was taken into the care of the Local Authority when she was thirteen and currently lives alone in a hostel north of London. She is currently studying for a Health and Social Care qualification at Further Education College.

26. Sefu is fifteen and was born in the UK to Ugandan parents. He has lived in the UK all his life. His parents came to the UK as overseas students, both are HIV positive. He lives with his family in the Midlands with his two older sisters who are not infected. He is currently at school.

27. Jahia is fifteen and was born in Zambia to Zambian parents and has lived in the UK since she was two. Her parents are divorced and both are HIV positive. She has lost four aunts and four uncles to HIV in Zambia and lives with her mother and older sister in London with her father and maternal aunt nearby. Her sister is not infected. Jahia is currently at school.

28. Joanna is eighteen and was born in Romania; she was adopted when she was one by British parents. She lives with her family in the Midlands; her brother and sister were also adopted from Romania. She has two step brothers and sisters from her father's first family with whom she has little contact. She is the only one in the family infected with HIV and is currently studying for a nursing diploma.

322

322

Characteristics of Participants

1. Ben is seventeen and is British. His father died from HIV when he was seven. Ben's parents were infected with HIV through intravenous drug use. He lives on his own in his mother's flat in northern England. His mother lives abroad and visits him regularly. Ben is at Further Education College studying animation and currently has a girlfriend.
2. Paul is twenty-four and was born in the UK, his parents came from Zambia. His parents are both dead. His mother and older brother died from HIV. Paul was five when his mother died and thirteen when his brother died. His aunt also died from HIV. He and his brother were cared for by social services. He currently lives on his own in London and has a child. He dropped out of college and works in the voluntary sector.
3. Asha is twenty-three and was born in Zambia and came to the UK when nine. Her mother died from HIV in Zambia when she was nine. She was cared for by her father and step-mother, she has step brothers and one step-sister that are not infected with HIV. She currently lives on her own but has contact with her father. She has a degree and wants to pursue a career in youth work.
4. Mark is eighteen and was born in the UK; his parents are both from Uganda. He lives in London with his mother and grandmother who brought him up. He has no contact with his father. HIV has affected his eyesight and consequently he has very poor vision. He currently works as a waiter, but wants to work in the music industry.

5. Neema is seventeen and was born in the UK to Ugandan parents. She has two brothers, one died from HIV when he was two years old and the other is not infected. Her aunt also died from HIV. Neema's parents are separated and she lives with her mother and brother in the South West of England. She plans to go to University and wants to work in health and social care.
6. Denisha died in 2009 at eighteen. She was born in Ghana and came to the UK when two. Her mother died from HIV in Ghana and her father died in the UK when she was twelve. She was brought up by her step mother and lived with her sister in London.
7. Amy is eighteen and was born in the UK. Her father died in Zambia from HIV. She was raised by her grandparents on the South coast as her mother was unable to care for her. Her mother was on drugs and supported Amy by selling sex. Her grandmother died when she was sixteen. She became a mother at 16 and lives with her boyfriend and is unemployed.
8. Alica is nineteen and was born in the UK, her mother is from Thailand and her Father is white British. Her parents are divorced and her younger sister, who is also HIV positive, lives with her father in the Midlands. Alica lives in London with her mother who has mental health problems. She works as a legal secretary.
9. Matthew is eighteen and was born in the UK, his mother is Kenyan and his father is from the UK. His mother died when he was two. He grew up in the Home Counties with his father and maternal aunt and is currently at university. He wants to study medicine.
10. Ruth is twenty and was born in Uganda to Ugandan parents. Her father and aunt died from HIV. She was three when she came to the UK and lived with her mother

and sister in London. She has nine other siblings. Her mother and two brothers are HIV positive. She plans to go to University but is currently unemployed.

11. Charlotte is nineteen and was born in the UK. Her parents died from HIV before she was five. Her father was Greek and her mother was from the UK. She lives with her maternal grandmother. She has very poor health but hopes to train as a social worker and work with children.
12. Jamelia is twenty and was born in Uganda to Ugandan parents. Her father, four aunts and two uncles have died from HIV. She came to the UK when she was four. She grew up in London with her mother. Her two brothers do not have HIV. Jamelia is currently unemployed.
13. Elijah died in 2009. He was twenty. He was born in Zambia to Zambian parents who both died from HIV before he was five. Six uncles and aunts have died from HIV. He was brought to the UK by his maternal aunt and uncle when he was five and they raised him. His uncle is also HIV positive. He lived independently in London and loved music.
14. Samuel is nineteen and was born in Zambia to Zambian parents. He came to the UK when he was eight. His father died of HIV when Samuel was seven and his mother brought him to the UK with his brother. His brother is not HIV positive. He lives independently in a bed-sit as his mother has returned to Zambia. He is at college studying business studies and plans to return to Zambia.
15. Louisa is seventeen and was born in Uganda to Ugandan parents. Her father died from HIV when she was four. One aunt has died from HIV in the UK and one in Uganda. She came to the UK when she was two. She lives in London with her mother and step father who are both HIV positive. Her maternal aunt is also HIV

positive. She has one sister, six half sisters and four half brothers. She is currently doing her A' levels at college.

16. Carmel is eighteen and died in 2009. She was born in Zambia to Zambian parents.

Her mother died when she was four and had no knowledge of her father. Her brother died at seventeen and five aunts and three uncles died from HIV in Zambia. She came to the UK when she was three. She had five brothers and was raised by her grandmother who died in 2009. She wanted to work in performing arts.

17. Callum is eighteen and was born in Zimbabwe to Zimbabwean parents. He came

to the UK when he was ten. He lives with his mother and brother in the Midlands area. His mother, father, brother and uncle are HIV positive. One aunt and uncle died from HIV. He is deaf as a result of the HIV virus and medication. His parents are divorced and he attends Art College and hopes to go to University to study art.

18. Joshua is twenty-two and was born in Uganda to Ugandan parents. His mother

and father both died from HIV and several aunts and uncles have died from HIV. He came to the UK with his sister when he was eleven and they lived in bed and breakfast accommodation for some years, but he now lives in a flat on his own in the London area. He left school at sixteen and went onto college but failed the course and he is currently unemployed.

19. Jonas is sixteen and was born in the UK to Ugandan parents. He lives with his

family in the Midlands. Both his parents and younger brother are HIV positive. He has problems with mobility due to spasticity in his legs which has required several operations. He is currently at school doing A levels.

20. Lakeesha is seventeen and was born in Djouboti. Her parents came to the UK when she was two. Her parents are divorced and she lives with her mother, brother and sister in London. She is currently at school and plans to go to university.
21. Elly is fifteen and was born in the UK. Her mother died from HIV when she was four. She lives with her father and stepmother in the Midlands. She has two half-sisters and is the only one infected in the family. She is currently at school.
22. Catriona is seventeen and was born and adopted in Romania. She lives in the north of England with her adopted parents. She has an older brother and sister who are married and have families. She is the only one infected in the family. She has been studying beauty therapy for two years at college. She has a boyfriend and plans to set up her own business.
23. Becka is seventeen and was born in Kenya, her mother is Kenyan and her father is from the UK. Her father brought her to the UK when she was two and since has had no contact with her mother. She lives in the north of England and has two older sisters and one half-brother. Her father has re-married and she is the only one infected with HIV in her family. She is currently at school doing A levels.
24. Jina is seventeen and was born in Zambia to Zambian parents. Her father died from HIV. Most of her extended family in Zambia have also died from HIV. She came to the UK when she was three and lives with her mother, step-father and three step-brothers on the South coast. She is currently at Further Education College studying nursing.
25. Rebecca is seventeen and was born in Zimbabwe to Zimbabwean parents. Her father died from HIV in Zimbabwe and many members of her extended family have

died from HIV. She came to join her mother in the UK when she was eleven. She was taken into the care of the Local Authority when she was thirteen and currently lives alone in a hostel north of London. She is currently studying for a Health and Social Care qualification at Further Education College.

26. Sefu is fifteen and was born in the UK to Ugandan parents. He has lived in the UK all his life. His parents came to the UK as overseas students, both are HIV positive. He lives with his family in the Midlands with his two older sisters who are not infected. He is currently at school.

27. Jahia is fifteen and was born in Zambia to Zambian parents and has lived in the UK since she was two. Her parents are divorced and both are HIV positive. She has lost four aunts and four uncles to HIV in Zambia and lives with her mother and older sister in London with her father and maternal aunt nearby. Her sister is not infected. Jahia is currently at school.

28. Joanna is eighteen and was born in Romania; she was adopted when she was one by British parents. She lives with her family in the Midlands; her brother and sister were also adopted from Romania. She has two step brothers and sisters from her father's first family with whom she has little contact. She is the only one in the family infected with HIV and is currently studying for a nursing diploma.